The nature, determinants and effects of medication beliefs in chronic illness.

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The nature, determinants and effects of medication beliefs in chronic illness

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Thesis presented for the degree of
Doctor of Philosophy
Faculty of Medicine
University of London

Field of study: Psychology

March 1997

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Acknowledgements

I would like to thank my supervisor, Professor John Weinman for his enthusiasm, guidance and encouragement and for smoothing the transfer between disciplines with humour and understanding. He has been generous with his time and expertise and I have learned a great deal from him. Warm thanks are also due to my partner Carol who supported me throughout this work.

I am grateful to Matthew Hankins for statistical advice and for coolness under pressure. A number of colleagues have also supported this work and I would like to thank Dr Pamela Graham, Professor Stephen Denyer and Graham Davies at the School of Pharmacy, University of Brighton and Professor Richard Vincent. I am indebted to Tony West and Robert Lea for their help with this venture and to Professor Terry Stacey for providing the coal which fuelled the write up.

I would also like to acknowledge a number of colleagues who made important contributions to this thesis. Early discussions with Professor Marie Johnston helped to focus my ideas. To Professors Howard and Elaine Leventhal for helpful discussions and permission to use the Sensitive Soma scale. I also benefited from the advice of Assistant Professor Keith Petrie, and Professor Jamie Pennebaker and from discussions with other colleagues including Professor Nick Barber, Dr Nicky Britten and Dr Myfanwy Morgan and from proof reading by my father Emlyn.

This thesis was supported by a research award from the Pharmacy Enterprise Scheme, Department of Health, UK and I am grateful to Jeannette Howe, Sue Ambler and Diane Kenworthy for their help.

I would like to thank Railton Scott, Angela Lashau, Barry Jubraj and David Goode who helped with data collection from the undergraduate students and the asthma, diabetes, renal and psychiatric illness samples. Thanks are also due to Alice Ward, Linda Dodds and the pre-registration pharmacists of South East Thames who collected data from the cardiac and general medical groups.

Finally, I would like to acknowledge the patients, students and clinicians who contributed their time and thoughts to this thesis

ABSTRACT

This thesis centres on an exploration of the nature, effects and determinants of beliefs about medication in the context of chronic illness. The literature review begins with a critical evaluation of adherence research with particular emphasis on the application of social cognition models and self-regulatory theory. Following this there is an overview of research eliciting beliefs about medicines which will clarify the outstanding questions.

The empirical section is divided into three parts. The first focuses on the nature of medication beliefs. Items derived from interviews with patients (n=35) and from themes identified in the literature were subjected to principal components analysis to identify the core dimensions underlying beliefs about medication prescribed for a particular illness (Specific) and more general beliefs about medicines as a whole (General). These dimensions form the Beliefs about Medicines Questionnaire (BMQ), which was found to have satisfactory psychometric properties. The BMQ was then used to investigate the distribution, effects and determinants of medication beliefs in a series of analyses on cross-sectional data obtained from 524 patients from a range of chronic illness groups.

The results show that lay beliefs about medicines are structured around four simple factors which were stable across illness groups. Core beliefs about prescribed medication are its perceived necessity for maintaining health (*Specific-Necessity*) and concerns about long-term effects and the potential for dependence (*Specific-Concerns*). The core beliefs about medicines in general are that they are intrinsically harmful, addictive substances (*General-Harm*) which are overused by doctors (*General-Overuse*). There were quite large differences in medication beliefs between and within illness groups. Although 87% of patients believed that their prescribed medicines were necessary, over a third expressed strong concerns. Age and beliefs about prescribed medication explained 27% of the variance in reported adherence. Patients with stronger concerns about their medication and weaker beliefs in its necessity reported lower adherence as did younger patients. A critique of the findings identifies directions for future research and practical applications.

INTRODUCTION

This thesis is concerned with the exploration of patients' beliefs about medicines. It arises from the well documented problems in adherence to medication. The main aim of the research is to identify and quantify patients' beliefs about medicines in order to explore their explanatory role in medication adherence.

Thus the literature review begins with an overview of adherence research which is followed by an examination of the role of beliefs and cognition in health, with particular emphasis on social cognition models and self regulatory theory. The final part of the literature review examines existing studies which have specifically focused on medication beliefs, primarily from a qualitative perspective. This identifies the outstanding questions, arising from the limitations of existing research which are addressed in the empirical section of the thesis

CHAPTER 1

Adherence to medication: definitions and measurement

1.1 Medicine taking in context: rationale for the study of adherence to medication

One of the dominant features in the development of medicine during the twentieth century has been the exponential growth in the number of effective drug treatments. The discovery of potent antibiotics during the 1940's was followed by a "therapeutic revolution" in which the burgeoning pharmaceutical industry produced a range of pharmacological active compounds for use in a wide variety of diseases. The prescription of a medicine is now one of the most common medical interventions and accounts for approximately 11% of expenditure within the UK National Health Service (NHS) (National Association of Health Authorities and Trusts, 1994).

The delivery of health care within the United Kingdom and other developed economies is based on a biomedical model in which ill-health is attributed to *diseases* which arise from disturbances in physiological functioning. Interventions based on this model are therefore characterised by the search for a specific disease label and the selection of a particular treatment which is deemed to be suitable for that particular disease. The biomedical model assumes that diseases are manifested in the body and are separate from psychological and social interactions of the mind. Outcome is determined by the nature and extent of the disease and the efficacy of the treatment. However, the suitability of this model in explaining differentials in health outcomes has been called into question (Engel, 1977) and it is now widely recognised that psychological (Kaplan, 1990; Berkman and Breslow, 1983; Pennebaker, 1982) and socio-economic factors (Wilkinson, 1990; Marmot et al. 1984) may have a profound influence on the aetiology and outcome of disease. The limitation of the biomedical model in explaining health outcomes stimulated the adoption of the biopsychosocial model which conceptualises health and illness as the product of a complex interaction between psychological, social and biological factors (Engel, 1980). This approach underpins the discipline of health psychology which is concerned with the study of psychological and behavioural processes in health and health care (Johnston, 1994).

Few issues identify the limitations of the biomedical model with greater clarity than that of adherence to medication, since it is generally acknowledged that many patients fail to follow prescription instructions and non-adherence to medication is viewed as a significant health problem (Ryan and Birch, 1991; Meichenbaum and Turk, 1987). If the prescription was appropriate and potentially effective then the degree of benefit to the patient will, to an extent, depend on how closely they follow the instructions for use. Non-adherence is a concern for those providing, receiving or funding care because it not only entails a waste of resources but also a missed opportunity for therapeutic benefit. Whilst attempting to explain the nature and extent of medication non-adherence the remainder of this chapter will highlight issues and controversies concerning the definition and assessment of adherence.

1.2 The nature of adherence: concepts and controversies

Major advances in medical technology which have occurred in the latter half of the twentieth century mean that the mortality and morbidity associated with many common diseases has been greatly reduced. Thus, in developed economies a key challenge for health intervention is to maximise the benefit of existing therapies by facilitating the appropriate self-management of common chronic illnesses, such as heart disease, asthma and diabetes. Non-adherence to medication is perceived as a significant barrier to this aim and has been identified as a cause for concern in most serious illnesses including heart disease (Horwitz et al. 1990; Monane et al. 1994), asthma (Yueng et al. 1994), diabetes (Glasgow et al. 1986), cancer (Lilleyman and Lennard, 1996), kidney disease (Cleary et al. 1995) and following organ transplantation (Hilbrands et al. 1995).

The incidence of reported medication non-adherence varies greatly from 4-92% across studies, converging at 30-50% in chronic illness (Meichenbaum and Turk, 1987; Haynes et al. 1979). The reasons for such a wide variation in the reported incidence are complex and relate to discrepancies in the definition and measurement of adherence across studies. The remainder of the chapter will outline some of the issues and problems associated with the definition and measurement of medication adherence. Before doing so, it is necessary to explain the rationale for the use of the term 'adherence'.

Until relatively recently the most common term for following treatment instructions was 'compliance'. However, this term has been criticised on the grounds that it has unfavourable connotations in terms of the doctor-patient relationship (Stimson, 1974).

Compliance seems to denote a relationship in which the patient has a passive role and is expected to 'follow the doctor's orders'. Failure to do so may be regarded as deviant behaviour and non-compliance may be seen as the patient's fault. The term 'adherence' has been adopted by many as an alternative to compliance, in an attempt to emphasise that the patient is free to decide whether to adhere to the doctor's recommendations and that failure to do so should not be a reason to blame the patient. Thus the impetus for a change in terminology from compliance to adherence was not simply a desire to be 'politically correct', but an attempt to acknowledge the role that patients should play as active collaborators in the therapeutic experiment. It follows that health care professionals (HCPs) have a responsibility to facilitate adherence to the treatment regimen they prescribe, rather than assuming that it is the patient's responsibility to comply with their instructions. These issues will be dealt with in the following sections which outline some of the main issues in the conceptualisation of the adherence/compliance construct. In the remainder of this thesis the term 'adherence' will be used in the spirit of conceptualising medicine-taking as a partnership between patient and HCP.

1.3 Controversies in the definition of medication adherence

Adherence may be simply defined as:

"*The extent to which the patient's behaviour coincides with the clinical prescription*" (Sackett and Haynes, 1976)

This is a succinct and pragmatic definition but it raises several conceptual and methodological issues (Gordis, 1979). The key problem here is how to define non-adherence. This is simple if adherence may be conceptualised as an "all or nothing" response in which the patient either follows the prescriber's instruction to the letter (adherence) or deviates from it in some way (non-adherence). However, the clinical utility of such a strict categorical definition is limited. For most medicines, the need for total adherence is questionable. Medication dosage regimens are usually derived from dose-response data obtained from clinical trials. Variations in response to standard doses of medication observed between and within individuals mean that standard recommended dosages for most medicines are approximate. They represent the dose which is most likely to accrue maximal therapeutic benefit with minimal harm for most patients most of the time. Thus, small deviations in adherence may add little to the variation in response inherent within the use of standardised dosages (Gibaldi, 1991).

The fact that less than 100% adherence may be sufficient to bring about the desired therapeutic response led Gordis to produce an alternative criteria for conceptualising non-adherence as:

"The point below which the desired preventative or desired therapeutic result is unlikely to be achieved" (Gordis, 1979)

This definition raises the important question: "When does non-adherence become clinically significant?" Many researchers and clinicians are understandably attracted to the idea of being able to categorise a patient as adherent or nonadherent. Indeed, this practice was once considered essential (Gordis, 1979). However, Gordis also identifies a drawback of dichotomising adherence behaviours by providing an example of how a range of behaviour patterns could be labelled as 50% adherence as illustrated in Figure 1.1, which typifies the limitations inherent in a concept of adherence as uniform construct of doing or not doing as instructed (Karoly, 1993). The problem is where to draw the line separating adequate adherence from inadequate adherence.

Patient 1	-	-	-	-	-	+	+	+	+	+
Patient 2	+	+	+	+	+	-	-	-	-	-
Patient 3	+	-	+	-	+	-	+	-	+	-
Patient 4	+	+	-	-	-	+	+	-	+	-

Figure 1.1 Hypothetical results of sequential tests in four "50% compliers" (Gordis, 1979)

The percentage adherence necessary to achieve the desired effect varies between medications and between and within individuals. Thus, ideally the percentage adherence necessary to achieve benefit would need to be established for each individual patient and medication. Faced with this problem, most researchers have taken a pragmatic approach, contending that: if the selection of the type and dose of medication has been made on the basis of clinical trial results and is appropriate, it is reasonable to assume, that the more the patients' behaviour approaches the prescriber's instructions then the more likely they are to benefit from the treatment. This can be applied to an incremental or categorical conception of adherence. Evidence suggests that this approach is not unreasonable. For example, in a study of hypertensive patients, 80% adherence to the regimen was sufficient to normalise blood pressure whereas 50% adherence was insufficient to control blood

pressure (Luscher et al. 1985). A separate study of recovery rates following myocardial infraction revealed that patients who took >75% of prescribed medication were approximately three times as likely to have survived after one year than those who took <75% (Horwitz et al. 1990).

However, a uniform approach in which adherence behaviour is dichotomised into "adherence and "nonadherence" remains problematic as the precise cut-off point will vary between patients and treatments. Moreover , the point at which nonadherence becomes detrimental will also depend on whether the prescription was appropriate. Sackett and Haynes (1976) conceptualise treatment as a 'therapeutic experiment', the outcome of which is influenced by actions of the practitioner, in selecting an appropriate diagnosis and treatment, as well as the patent in adhering to the regimen. This concept is illustrated by Figure 1.2.

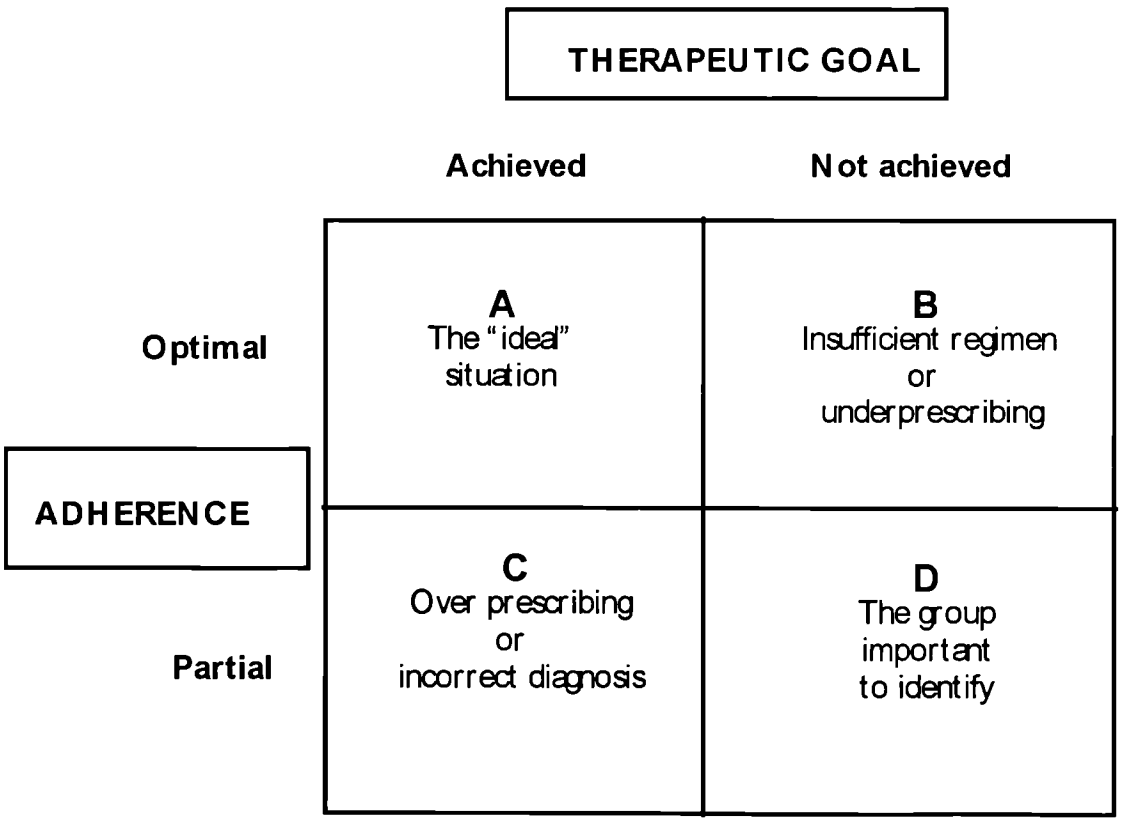


Figure 1.2 Possible outcomes in the therapeutic experiment. Adapted from Sackett, Haynes and Tugwell (1985)

Recognising the fallibility of the practitioner as prescriber emphasises the point that high adherence does not necessarily result in benefit to the patient. It highlights the fact that patients and practitioner carry mutual responsibility for the outcome of the therapeutic experiment. The notion of shared responsibility is now generally extended to the issue of adherence. Most current reviewers maintain that HCPs have a responsibility not only to select the appropriate treatment but also to facilitate adherence to the regimen. This is in sharp contrast with the view that it is the patient's responsibility to take the medication as instructed and that failure to do so is a fault of the patient alone. The notion of shared responsibility for adherence has arisen in response to some of the ethical dilemmas raised by nonadherence. These issues are summarised in the following section but are discussed more comprehensively by Jonsen (1979)

1.4 Ethical issues in conceptualising adherence

Certain ethical issues are raised by the conceptualisation of adherence. The first concerns *blame*. Health Care Providers are often frustrated by non-adherence and there may be a tendency to view the "non-compliant patient" as deviant or ungrateful and that this behaviour should be corrected. Approaching the issue from this standpoint is at odds with the "*ethical ideal of freedom, mutual understanding and mutual responsibility*" set out by Jonsen (1979). This ethical ideal is represented in Fink's consensual regimen:

> *"A negotiated mutual contract in which both provider and client can be said to have given 'informed consent', which is practical in terms of the current set of health problems and resources, 'no-fault' attitudes towards noncompliant behaviour , and mutual responsibility for outcome"*
> (Fink, 1976)

Implicit in Fink's approach is the notion that Health Care Providers have a responsibility to facilitate adherence to their treatment regimen rather than assuming that it is the patient's responsibility to comply with their instructions. Accepting this premise intensifies the need for a greater understanding of why patients do or do not adhere to treatment instructions, in order to guide interventions which facilitate appropriate consensual adherence. Haynes, Taylor and Sackett (1979) have suggested several criteria which must be met before intervention is deemed to be ethical :

- The diagnosis must be correct (and the treatment appropriate)
- The therapy must do more harm than good
- The patient should be an informed willing partner in any intervention designed to alter behaviour

1.5 Types of nonadherence to medication

Three broad categories of medication non-adherence have been described in the literature:

Original prescription not filled Studies have shown that 5-20% of primary care patients fail to present the prescription for dispensing in the first place and this has been termed primary non-compliance (Beardon et al. 1993; Rashid, 1982; Begg, 1984).

Refills not obtained This problem was illustrated by a recent study in which only 10% of a sample of over 7000 patients with chronic heart failure filled enough prescriptions to ensure a regular daily supply of medication (Monane et al. 1994).

Incorrect dosing Most of the published studies in the adherence area have focused on what the patient does with the medication once it has been dispensed. In this context adherence may be *categorical* or *incremental* . In categorical definitions patients are judged to be adherent or non-adherent based on the amount of medication taken in relation to a defined 'cut-off' point. Incremental definitions conceptualise adherence as a continuum.

1.6 Active and passive non-adherence

Non-adherence behaviours may be categorised according to the degree of volition. Active non-adherence (AnA) arises when the patient makes a strategic decision not to take the treatment as instructed. This has also been called "intelligent non-compliance" in recognition of the fact that viewed from the patient's perspective non-adherence may be the result of a rational decision (Weintraub, 1990). This term is problematic as some might see it as value-laden, implying that unintentional nonadherence is somehow characteristic of a lack of intelligence.

In *active* nonadherence (AnA), the behaviour is under-pinned by a strategic motive. The patient makes a decision not to follow the treatment regimes or deliberately alters it or some reason. An example of this type of behaviour was found among hypertensive patients who, believed that they could judge when their blood pressure was high by the presence of symptoms such as stress or headache and thus took anti-hypertensive medication only when these symptoms were experienced (Baumann et al. 1989; Meyer and Leventhal, 1985). Active nonadherence behaviour has been noted among several chronic illness groups including asthma (Becker et al. 1978; Woller et al. 1993), rheumatoid arthritis (Lorish et al. 1990), epilepsy (Conrad, 1985) and hypertension (Morgan and Watkins, 1988).

Passive non-adherence (PnA) may be unintentional when the patient's intentions to take the medication are thwarted by barriers such as forgetting, and inability to follow treatment instructions because of a lack of understanding or physical problems such as poor eyesight or impaired manual dexterity. PnA may not be completely without volition since it might arise from a lack of motivation to adhere to the regimen, rather than an *active* decision to adjust or omit doses (Cooper et al. 1982).

1.7 Measurement of adherence

As with many other areas of scientific research, an accurate measurement technique is necessary to characterise the prevalence and determinants of adherence and to evaluate interventions to enhance it. Unfortunately, the measurement of adherence is as problematic as its conceptualisation and definition, and poses many challenges, some of which are unique to medication while others apply to most behaviours. The following section will summarise key issues in assessing medication adherence, followed by a brief overview of the available methods. Three methods of adherence assessment which are considered to be particularly relevant to this project will be reviewed in more detail. These are the low dose phenobarbitone (LDPB) marker, medication event monitoring system (MEMS) and patient self-reports.

1.8 Methodological issues in the assessment of adherence to medication

1.8.1 Accuracy

Two aspects of accuracy are particularly salient in adherence measurement, namely specificity and sensitivity. *Specificity* refers to the proportion of false negatives and is typically expressed as the proportion of cases of nonadherence identified by the test method which are corroborated by a 'gold standard' measure. *Sensitivity* based on the frequency of false positives and refers to the proportion of cases of high adherence identified by the test measure which are corroborated by the 'gold standard' (Morisky et al. 1986) measure. Sometimes a test measure is expressed as a *percentage accuracy* reflecting the percentage of cases which were correctly classified by it.

1.8.2 Reliability

In the psychometric literature the reliability of a test refers to its reproducibility. In the adherence literature 'reliability is often confused with accuracy. Authors sometimes use the term 'reliability' when discussing the accuracy of an adherence measure in terms of the rates of false positives or false negatives compared to some standard criteria, rather than the test-retest reproducibility. Good test-retest reliability does not mean that the method is accurate. It may simply be that inaccuracies are consistently reproduced (Caron, 1985). However, reliability is a key issue if the method is to be used to detect changes in adherence behaviour.

1.8.3 Measurement as a source of bias

One of the difficulties of measuring behaviour is that the act of measurement can itself influence behaviour. The tendency for observation to influence behaviour is often referred to as the Hawthorne effect after the series of experiments investigating employee satisfaction and productivity conducted in Hawthorne, Chicago (Roethlisberger and Dickson, 1939). Thus, if the patient is aware that their adherence is being monitored this might stimulate adherence simply by drawing attention to the activity. The tendency of attention from others to influence behaviour is known in psychology as *reactivity* (Reynolds, 1982; Haynes and Horn, 1982). The measurement of adherence is also vulnerable to self-

presentational bias on the part of the patient (Sheeran and Orbell, 1996). Patients may perceive that adherence to treatment is one of the duties expected of the "good patient" and may be reluctant to display non-adherence because they fear that this will offend or disappoint their doctor or risk their disapproval. Consequently, in an attempt to present themselves as more adherent, patients may create a falsely elevated adherence score by taking more medication immediately prior to testing or by under-reporting nonadherence (Rudd, 1993).

1.8.4 Characterising adherence behaviours

As discussed in the previous section, patients adherence behaviour may vary over time. Thus, assigning a patient to an adherent vs. nonadherent category on the basis of a single isolated measurement may be less meaningful than detailing the type (e.g. active vs. passive) and its profile over time.

1.8.5 Ethical issues

Researchers wishing to measure adherence face a dilemma. Making the patient aware that their behaviour is being assessed may alter it or lead to self presentational bias. Conversely, failure to inform patients that they are being monitored may be deemed unethical. This is particularly salient when the method of assessment is invasive and permission to conduct the assessment must be obtained in advance. Eliciting permission might alert the patient to the fact that are being monitored and thus act a source of bias. Moreover, the discovery of surreptitious monitoring by the patient may have an adverse effect on the patient-practitioner relationship.

1.9 An overview of techniques for measuring medication adherence

Adherence measures can be divided into two broad categories according to whether the assessment is direct or indirect. Direct measurement entails observing the ingestion of the drug or by detecting its presence in body fluids. Indirect measures assume ingestion based on proxy evidence such as the patients report or number of dosages removed from a container. The strengths and weaknesses of available direct and indirect methods have been extensively reviewed (Creer, 1993; Rand and Wise, 1994; Rudd, 1993; Gordis, 1979) and these are briefly discussed below and summarised in Table1.1 and Table 1.2.

Table 1.1 Strengths and weaknesses of direct measures used in assessing medication compliance (adapted from Creer, 1993)

Strengths	Weaknesses
Blood Serum Assays	
1. Objective 2. Direct	1. Inter- and intra-patient variability in drug handling may reduce accuracy 2. Pharmacokinetic interactions with other medications may interfere with assay 3. Timing of assays in relation to dose 4. Long-term versus short-term medications 5. Pain and inconvenience to patients 6. Specialised equipment required 7. Lack of standardised criteria for judging compliance 8. Ethical restraints 9. Does not provide a profile of behaviour
Tracers or Markers	
1. Objective 2. Direct	1. Timing of testing 2. Specialised equipment required 3. Marker of tracer may interact with other substances 4. Provides qualitative rather than quantitative data 5. Does not provide a profile of behaviour
Direct Observation	
1. Objective 2. Direct 3. Yields quantifiable data 4. May provide a profile of behaviour	1. Obtrusive 2. Reactivity is likely to occur (observation may constitute an intervention) 3. Observer may become involved 4. Requires training of observers 5. Not feasible for physician use over extended periods of time 6. Ethical restraints

Table 1.2 Strengths and weaknesses of indirect measures used in assessing medication compliance

Strengths	Weaknesses
Patient Reports	
1. Few ethical restraints 2. Easily obtained information 3. Inexpensive 4. Measures which are psychometrically sound have construct and predictive validity 5. Non-invasive	1. Overestimated adherence 2. Underreports nonadherence 3. Less accurate than other methods 4. Subject to recall and self-presentational bias
Pill and Liquid Medications Assessment	
1. Easily obtained 2. Inexpensive 3. Surreptitious assessment may be reasonably accurate (but may be unethical) 4. Non-invasive	1. May overestimate compliance • pills may be removed but not ingested • does not delineate consumption patterns • pills may be taken by other family members 2. Inherent difficulties occur in measuring liquid medications 3. Does not provide a profile of behaviour
Electronic Measurement Devices	
1. Objective 2. Provides a profile of adherence behaviour	1. Assesses use of containers or devices, not medication 2. Requires expensive equipment 3. Instrument malfunction may occur 4. Reactivity may occur if patient is informed of monitoring
Treatment Outcomes	
1. Readily available to clinician 2. Non-invasive	1. Lacks precision 2. Influenced by such factors as: • misdiagnosis • incorrect treatment • spontaneous remission of symptoms 3. Does not provide a profile of behaviour
Prescription Refill Records	
1. Unintrusive and surreptitious 2. May be used to augment self-report 3. Inexpensive	1. Indicates collection of medication not usage 2. Requires co-operation of doctor and pharmacist 3. Patient may present prescriptions to different pharmacies

1.10 Direct methods

These methods are termed 'direct' because assessment focuses on the presence of a drug or a tracer compound such as riboflavin (Creer, 1993), in body fluids as evidence that the medication has been taken. At first sight this might appear to be the best way to assess adherence as other methods do not directly confirm that the medication has been ingested (Caron, 1985) However, these techniques are fraught with problems, chiefly that the relationship between the amount of medication or tracer taken and the concentration found in body fluids is at best precarious. There is often considerable variation in drug absorption, distribution, metabolism and elimination between individuals and within the same individual over time (Gibaldi, 1991). It is particularly difficult to relate urinary drug or tracer concentrations to administered dose, and drug/urine concentration is regarded as a qualitative indicator of whether some of the drug has been taken, rather than a quantitative measure of how much (Gordis, 1979). The validity of serum drug concentrations as a measure of amount of drug ingested is also compromised by differences in drug handling between and within individuals. For many drugs, particularly those which are quickly eliminated from the body the results obtained depend on the time of sampling.

The major drawback of direct methods is that they are invasive, expensive, of questionable reliability and provide no indication of the type or time-course of nonadherent behaviour. Additionally, valid reliable assays are routinely available for relatively few drugs.

The recent use of low dose phenobarbitone as a pharmacological tracer has stimulated renewed interest in direct measures and has been hailed by some as a potential gold standard (McGavock, 1996). In this technique, the medication under study is combined a small dose of phenobarbitone. The fact that phenobarbitone is only slowly eliminated from the body coupled with the use of sophisticated Baysian statistical modelling techniques, provides a quantitative indication of the amount of drug ingested. A further advantage is that phenobarbitone can be accurately and reliably measured in serum concentrations which are thought to be low enough to avoid adverse effects (Pullar et al. 1989; Feely et al. 1987).

However, the method has several limitations. Its accuracy is dependent on time of sampling in relation to the administered dose (Pullar et al. 1991). In practice, this means

that if a patient's observed plasma PB concentration is similar to that expected, the researcher must question whether this is attributable to a high adherence level or represents a peak plasma level (taken about 6-8 hours after administration of the dose) obtained from a patient with lower adherence. This means that even this apparently objective method of adherence assessment may be at least partially compromised by the perceived subjectivity of patient self-report. In most cases, the source of information about the time when the last dose was taken is likely to be provided by the patient. The method shares the ethical limitations of other direct methods. The fact that medication has to specially formulated to include the marker adds to the cost and may give the patient advance notice that their adherence is being monitored and introduce reactivity and self-presentational bias. Thus, although the LDPI technique represents a technological advance the inherent limitations outlined above mean that it cannot be adopted as a "gold standard" for routine use in adherence studies. It is most commonly used in clinical trials in combination with other adherence assessments.

1.11 Direct observation

The patient's medication taking behaviour is observed directly by a researcher or clinical or member of the patient's family. This method is prone to reactivity bias and is impractical in most research situations. Moreover, asking family members to gather data on the patients' adherence behaviour is ethically problematic as it might compromise their relationship. Patient diary cards have also been used to assess adherence but this is clearly an intervention which might influence adherence in its own right. Also asking the patient to fill out a diary represents another instruction which is subject to variations in adherence (Rand and Wise, 1994).

1.12 Indirect methods

1.12.1 Pill counts

A commonly used method for assessing adherence is to count the number of dosage units left in the container and compare this to the number which would have been left had the patient followed the instructions. This method has the advantages of being technologically simple and inexpensive. However, some studies have shown that pill count may under-estimate the true level of nonadherence (Rudd et al. 1990; Kruse et al. 1993). Although one can be reasonably sure that if the pill is in the container it has not been taken by the patient, there is no guarantee that a pill which has been removed for the container has

actually been ingested. Patients may remove medication for reasons other than to use it. They might give the medication to someone else, or transfer it to another container, or may deliberately discard doses prior to monitoring to create an impression of high adherence. This practice - known as 'dose-dumping' may be reduced by not alerting the patient to the fact that their pills will be counted. But this can be risky. For example in one study Haynes and colleagues (1978) used the rather bold technique of asking Canadian steel workers to 'provide a urine sample' and then surreptitiously counting their tablets while they were indisposed. Although this strategy appears to have been effective in this case, an early return, resulting in discovery of the researchers deception, might have irrevocably damaged researcher-patient rapport (Haynes et al. 1980).

A further source of inaccuracy associated with the method arises from the need to know when the container was started. Relying on the date of dispensing - included on the packaging label- may be misleading. Many patients receiving treatment for a chronic illness will obtain a supply of their medication in advance to avoid running out and so may start the package after it was dispensed. Patient's report of when they started the pack is subject to recall-bias. One problem that pill counts share with direct measures is that they do not provide a profile of medication taking.

1.12.2 Electronic monitors

These techniques involve the incorporation of electronic devices into the medicine container to record the time and date of usage. Early versions were bulky and inconvenient to use (McGavock, 1996), but recent advances in micro-electronic and computer technology have resulted in monitoring systems for tablet bottles, metered dose inhalers and eye drop-containers. Attention has focused on the Medication Event Monitoring System (MEMS) which comprises a microprocessor incorporated into the cap of an otherwise standard container (Cramer et al. 1989). Studies evaluating the MEMS illustrate the strengths and weakness of electronic measures in general.

The major advantage of these devices is that they potentially provide a profile of medication taking rather than simply detailing how much was taken (Kruse et al. 1993; Rudd et al. 1990; Kruse and Weber, 1990). However, as with the pill count method, a dose removed is not necessarily a dose taken. Furthermore, if inclusion of the monitoring devise changes the appearance of the medicinal product this will alert the patient to the fact that they are being monitored and may change behaviour. The devices are also

expensive and often need to be sent away for processing which may cause significant delay (Matsui et al. 1994) Several studies comparing the MEMS with pill count or self report indicate that other methods under-estimate the degree of non-adherence relative to MEMS (Rudd et al. 1989; Waterhouse et al. 1993). Other studies suggest that significant numbers of patients experience problems using the containers (Kruse et al. 1992), or remove medication for later use, leading to an overestimate of nonadherence (Matsui et al. 1994). The device is also limited if the dosage regimen requires the patient to take more than one dosage unit at a time.

In technical terms, the MEMS is the best available method for giving a profile of medicine taking over time and has a clear application in clinical trials. However, the above limitations mean that these techniques may not be appropriate for all studies. For example if the aim is to grade patients according to overall adherence rather than to provide a detailed picture of timing and frequency of dosing, then MEMS may offer no real advantage over pill counts (Matsui et al. 1994).

1.12.3 Patient self-report

One of the most commonly used methods of assessing adherence is simply to ask the patient. and self-report measures are widely used in adherence studies. However opinions about the value of this method are sharply divided. Some reviewers consider it to be useless because it overestimates adherence (Caron, 1985). Others maintain that it is a valid indicator of medication adherence which is practical and useful in a wide variety of research settings (Ley and Llewellyn, 1995; Meichenbaum and Turk, 1987). Why such a polarised view? One problem with self-reported adherence (SRA) is that questions about medicine taking are often presented at a time and place which is quite distant from the actual event and so reports are subject to recall effects. In particular, even when they admit to non-adherent behaviour, people tend to overestimate the extent of their adherence (Ley and Llewellyn, 1995). For example, in one study of hypertensive steel workers, even those who reported nonadherence overestimated the extent of their adherence by an average of 17% (Haynes et al. 1980). Recall bias of this type seems to increase with longer periods of requested recall and Rudd has suggested that the outer limit for reasonably accurate recall is about two weeks (Rudd, 1993).

Another issue relates to the truthfulness of SRA. Reviewers and PhD students are fond of pointing out that Hippocrates observed over 2,500 years ago that:

> *"(Physicians should) keep watch also on the faults of patients which often make them lie about the taking of things prescribed"*

This observation is corroborated by more recent authors demonstrating that patients often under-report non-adherence (Dunbar and Waszak, 1990; Gordis, 1979; Gordis et al. 1969). The accuracy of self-report as measure of adherence has been assessed by comparison with other, more objective, methods or evaluated on the basis of correlation between self-reported adherence and clinical outcome measures. In the main these studies show that the accuracy of self-report varies according to the type of adherence behaviour reported. Reports of low adherence are generally considered to be accurate as there is no evidence that patients misrepresent themselves as non-adherers (Rand and Wise, 1994). However, patient's reports of high adherence are often less accurate and discrepancies occur between the number of patients reporting high adherence and those registering high adherence rates by other methods. Thus SRA is often considered to have high specificity but low sensitivity. In some studies self-report may fail to detect approximately 50% of patients with low adherence (Haynes et al. 1980; Gordis et al. 1969).

Why does this rather disappointing statistic not curtail interest in this approach.? To answer this question we need to take a closer look at the methodologies used in these studies. A surprising number of studies by experienced and respected researchers provide very few details about the self-report measure. This is problematic because a key reason for under-reporting nonadherence is self-presentational bias (SPB) on the part of the patient. SPB may be reduced by altering situational variables, such as the phrasing of adherence related questions, to facilitate more truthful reporting by reducing the social pressures which lead to self-presentational . Thus, in judging the validity of self-report as a technique for assessing adherence it is important to consider the face validity of the items used to elicit reported adherence. In earlier studies, the self-report measures are crude with little attempt to control for SPB. For example, in one study which is often quoted in evidence against self-report, participants were simply asked by the attending physician if they had taken their medication that morning (Gordis et al. 1969) thus exerting social pressure to give an affirmative answer. In other studies few details of the adherence questions or the frequency of responses are given (Waterhouse et al. 1993; Roth and Caron, 1978). Even when attempts are made to control SPB, the questions used are psychometrically unsophisticated offering simple dichotomous responses rather than

continuous scales (Haynes et al. 1980). Another methodological problem is that SRA measures may be compared against 'objective measures' of questionable validity (Gordis et al. 1969). Stetcher and colleagues (1989) have pointed out that most studies revealing high rates of miss-reporting established only one cut-off point for determining whether or not the patient was adherent and argue that major deviations tend to be more accurately reported than minor ones.

It has been suggested that the validity of SRA measures can be enhanced by concurrent use of a clinical measure such as blood pressure control (Inui et al. 1981). However a few studies have demonstrated that SR measures alone are reasonably sensitive. For example in one study in which home interviews were conducted with patients ten days after they had received a prescription from a community physician, patients report that they had not missed a dose, were corroborated by surreptitious tablet count in 80% of cases (Stewart, 1987). Other studies have found a strong correlation between self report and direct measures of serum drug concentrations (Fletcher et al. 1979; Becker et al. 1978) and between self-report and pill counts (Waterhouse et al. 1993). Becker and colleagues (1978) found a high correlation (r=0.9) between mothers' reports of theophylline administration and covert assay of serum theophylline concentrations in 80 asthmatic children attending an emergency room. However, the emergency room situation may have exerted an external pressure on the mothers to accurately report their adherence and these results may not be easily extrapolated to other, less urgent, situations.

The validity of self-report measures of adherence seems to increase with the psychometric sophistication of the measure (Kravitz et al. 1993). Morisky and colleagues (1986) showed that a four item scale of adherence to anti-hypertensive medication had acceptable internal consistency (Cronbach alpha =0.6), and was moderately predictive of blood pressure control at 2 and 5 year follow ups. Respondents were asked to reply (yes/no) to each of four items shown in Table 1.3.

Table 1.3 Self-reported medication adherence scale (Morisky et al. 1986)

- Do you ever forget to take your medicine?
- Are you careless at times about taking your medicine?
- When you feel better do you sometimes stop taking your medicines?
- Sometimes if you feel worse when you take your medicine do you stop taking it?

The discriminant validity of a 6-item self-report scale of adherence to asthma medication based on Morisky's SRA scale (1986) was confirmed by the ability of the scales to detect the impact of an intervention to improve adherence (Brooks et al. 1994). A psychometric limitation of these scales is that responses to adherence questions are dichotomous. Extending the range of questions and using a 6-point scale (from none of the time to all of the time) for responses, resulted in the Medical Outcomes Study (MOS) adherence scale. This has acceptable criterion-related validity as demonstrated by correlation between scale scores and clinical outcome in a range of diagnostic groups: hypertension, diabetes and myocardial infarction (DiMatteo et al. 1993; Kravitz et al. 1993). However, this scale is not specific to medication. Further evidence in support of the validity of self-report measures comes from a study of medication adherence among paediatric and adolescent cancer patients (Tebbi et al. 1986). Medication adherence was measured by responses to non-threatening questions, about the frequency of missed doses during the preceding month were grouped into three categories of: no misses, occasional misses and frequent misses. Serum corticosteroid assays conducted in 16 patients corroborated self-report in every case.

A more detailed inspection of the SRA measures described above identifies room for improvement in the method used to control self-presentational bias or in the psychometric sophistication of the scale. For example the MOS-adherence measures items which are phrased in a non-judgemental way in an attempt to limit self-presentational bias (e.g. 'I had a hard time doing what the doctor suggested I do'). One criticism of this approach, however is that the sanctioning of non-adherence is implicit (i.e. adherence is difficult) and that self-presentational bias may be more effectively reduced by stating the sanction more explicitly. This is demonstrated by Fletcher and colleagues (1979) who preceded their adherence questions with the statement: 'Many patients have told me that they find it difficult to take all their medicine exactly as the doctor prescribed'. Patients were then presented with cards asking them to rate how often they took their medication rated as 0%, 25%, 50%, 74% and 100%. This approach is limited by the single item response. It is

also possible that numerical (eg 1-5) or statement (eg often, sometimes) are more easily interpreted by respondents than percentages.

In conclusion, although SRA may not provide an exact profile of the amount of medication taken over time, and is subject to inaccuracies of overestimating adherence, these can be reduced by controlling self-presentational bias and using psychometrically sound methods of eliciting SRA. In such circumstances there is evidence to support Ley's conclusion that SRA is: 'a useful method of grading patients on the adherence continuum' (Ley and Llewellyn, 1995). However there is room for improvement in existing measures. The availability of sophisticated electronic measuring devices such the MEMS should encourage further studies into the sensitivity and specificity of sophisticated SRA measures.

1.12.4 Other methods

Clinicians estimates: generally prove to be grossly inaccurate (Rudd, 1993; Norell, 1981) and do not improve with professional experience or familiarity with the patient (Roth and Caron, 1978), possibly because clinicians tend to base their estimates on patient's personality or sociodemographic factors.

Therapeutic outcome: as a measure of adherence is based on the assumption that there is a close relationship between adherence to treatment and clinical benefit.. Research has shown this to be true for certain effective treatments, appropriately prescribed (Horwitz and Horwitz, 1993). However, adherence does not guarantee benefit and the relationship between adherence and health outcome is rarely linear and quantifiable (Gordis, 1979). Although this relationship is used as a test of predictive validity of the measurement technique (Haynes et al. 1980; Morisky et al. 1986), it is not generally considered to be a valid measure of adherence behaviour.

Prescription-refill records: Pharmacy records have been used as a measure of primary nonadherence (Beardon et al. 1993) and as an indicator of adherence to chronic medication (Hamilton and Briceland, 1992). The frequency with which the patient orders and presents prescriptions for dispensing is compared with the expected frequency if the patient were using the medication as instructed. Deviations from expected usage indicate nonadherence. This method relies on the patient presenting their prescription to a single pharmacy. Studies are needed to determine the value of this rarely used but potentially helpful, method as a cross check of self-report data. For example, it might alert a

researcher to false self-report if the patient reports high adherence but has a very low refill rate.

1.13 Choosing an adherence measure

There is currently no 'gold standard' measure of adherence which can be used within the resource restraints of studies of illness behaviour outside the controlled conditions of clinical trials. Interpreting studies comparing the performance of various adherence measures is therefore difficult. Each of the methods discussed above has certain flaws which limit the accuracy, reliability or practical application of the technique. With the possible exception of electronic measurement devices such as the MEMS, most of the available techniques function as indicators of adherence rather than exact, quantitative measures of behaviour.

Thus the choice of adherence measures represents a compromise in which accuracy and comprehensiveness of the measure is balanced against reactivity, and practical ethical and cost limitations. In this analysis pychometrically sophisticated SRA measures appear to offer advantages in many situations. If there is any consensus in this complex issue it is that a variety of measures should be used where possible (Rand and Wise, 1994; Rudd, 1993; Meichenbaum and Turk, 1987; Gordis, 1979).

CHAPTER 2
An overview of adherence research

Despite the ethical and conceptual limitations of the adherence construct, a plethora of research studies have been conducted , over the last 25 years or so, in an attempt to identify the determinants of adherence and to develop effective interventions to enhance it. Adherence research has been characterised by three broad approaches:

(a) Atheortical approaches

Much of the early research and a portion of the later is atheoretical in its approach and represents a pragmatic attempt to identify the antecedents of nonadherent behaviour or to evaluate interventions to change it. The philosophical starting point for much of this research appears to be the notion of nonadherence as a state characteristic which may be linked to certain sociodemographic or dispositional features of the patient or as a simple lack of knowledge about the treatment regimen and how to use it.

(b) The communication model

This approach focuses on the role of communication and the nature of interactions between patients and HCPs. Although this work does not appear to be explicitly theory driven, it draws on an implicit theory that the quality of the patient's interaction with the HCP is of prime importance. This approach, which is typified by the work of Ley (1982, 1988), stems from the observation that patients often misunderstand or forget treatment instructions or may lack motivation to take the treatment because they are dissatisfied with some aspect of the doctor-patient relationship.

(c) The social cognition models and self-regulatory theory

This approach focuses on patient's beliefs and the sociocultural context in which they occur. It draws on a range of theoretical models, commonly refereed to as *social cognition models* (SCMs), which attempt to explain health-related behaviours in relation to specific cognitions (Stroebe and Stroebe, 1995). These include expectancy-value models such as the Health Belief Model (HBM) and Theory of

Reasoned Action (TRA) in which the decision whether or not to follow the treatment advice is based on the patient's expectations of what the treatment will achieve and the value which they place upon it. In contrast, Leventhal's self-regulatory theory views adherence as the product of a dynamic interaction between the patients experience of and beliefs about the illness, their emotional reaction to it and their appraisal of the impact of adherence/nonadherence on their well-being.

Each of the above approaches has been applied to two key questions: 'What are the determinants of adherence?' and 'How can adherence be enhanced?' The remainder of the chapter presents a summary of existing knowledge about the determinants of medication adherence derived from research using atheoretical approaches and the 'communication model'. A further section summarises the scope and limitations of intervention studies based on these approaches and their contribution to knowledge. This will be followed in Chapters 3 and 4 by a review of Social Cognition Models and Leventhal's Self-Regulatory Theory and their application to the study of adherence to medication.

2.1 The determinants of non-adherence: atheoretical and communications approaches

Early studies highlighting the prevalence of sub-optimal medicine taking were followed by an intense search for the determinants of non-adherent behaviours, which identified over 100 possible causes of adherence (Sackett and Haynes, 1976). It is not surprising that so many possible causes were identified given that most studies investigated univariate correlations between variables with few attempts to see whether associations held across socio-demographic or illness/treatment categories or to control for possible confounders (Rudd, 1993). Moreover, an assessment of the relative contribution of various factors to variance in adherence was rarely conducted and many single factors were found to be unimportant when interactions between variables were assessed or when studies were pooled or compared (Haynes et al. 1979; Sackett and Haynes, 1976).

It is possible to summarise the determinants of adherence identified in earlier studies into three categories:

- Characteristics of the disease and treatment regimen
- Patient characteristics
- Quality of interactions between patient and health care practitioner (HCP).

These categories are obviously not mutually exclusive and there is likely to be considerable overlap between them. However, they are often used as a convenient way of summarising the complex array of adherence antecedents identified in early studies (Meichenbaum and Turk, 1987).

2.2 Characteristics of the disease as determinants of adherence

There is circumstantial evidence that general levels of adherence may be higher in some conditions than others. For example Horwitz and colleagues (1990), reported that only 10% of patients recovering from a myocardial infraction were classed as non-adherent, whereas studies involving patients with hypertension tend to report higher levels with nonadherence rates averaging around 50% (Meichenbaum and Turk, 1987; Haynes, 1976). Similarly, adherence rates in acute conditions are often higher than in chronic disease, especially where treatment of the latter seems to produce little symptomatic benefit. Also, low adherence rates are thought to be particularly prevalent among patients with psychotic illnesses (Meichenbaum and Turk, 1987; Haynes et al. 1979). However, the fact that considerable variation in adherence is noted among patients with the same disease supports an interpretation that differential adherence rates arise from the effect of the disease on the individual, rather than from a property of the disease which has a generalisable effect on adherence in all patients. The focus for investigation should therefore be the patient and how they interpret or manage the challenges imposed by the disease.

2.3 Characteristics of the Treatment Regimen as determinants of adherence

2.3.1 Physical barriers to adherence

The formulation or packaging of the medication may act as a barrier to adherence. For example some patients may have difficulty in swallowing large capsules or may lack the manual dexterity to use complex dosage forms such as metered dose inhalers or to open blister packs or child-resistant containers. Patients with arthritic conditions may be particularly prone to these problems.

2.3.2 Complexity of the therapeutic regimen

There is fairly strong evidence to support the common-sense notion that the more complex the treatment demands then the lower the adherence (Meichenbaum and Turk, 1987; Haynes, 1976). There are several sources of complexity: the prescription of a large number of individual medications, the need to take medication at frequent intervals, or medications which are difficult to use, such as inhaler devices. Complex regimens carry the risk of information overload and related problems of poor understanding or low recall of instructions. Additionally, a complex regimen may be so disruptive to the patient's daily routine that they become demotivated and may avoid or delay doses (Meichenbaum and Turk, 1987). The observed correlation between regimen complexity and nonadherence seems to have led to the assumption in some quarters that simply reducing the frequency of dosing is enough to prevent nonadherence. This is often evidenced in the marketing of 'once daily' pharmaceuticals. However, there is little evidence to support the efficacy of this single strategy in enhancing adherence to medication (Haynes et al. 1979).

The fallacy of 'once daily dose' as a panacea for nonadherence is illustrated by a recent prospective study in which 89 depressed out-patients were randomly allocated to one of three, therapeutically equivalent, daily dosage schedules of the same antidepressant medication (amitripyline and mianserin) (Myers and Branthwaite, 1992). Group A received their medication at night, Group B in three divided doses and Group C were allowed a free choice between regimen A or B. Adherence rates did not differ according to whether the regimen was prescribed once or three times a day. However, patients who chose a three-times a day regimen were significantly more adherent. This and other recent studies reinforce the view that; although reducing the number of daily doses can facilitate adherence if frequency of dosing is a barrier for the particular individual in question, the routine choice of once-daily regimens is unjustified (Cramer et al. 1989; Eisen et al. 1990). Complexity *per se* is not the key issue but how well the treatment fits in with the individual patient's routine (Meichenbaum and Turk, 1987; Cockburn et al. 1987). It has been suggested that increasing the complexity of a dosage regimen during the course of therapy may reduce adherence because people find it difficult to 'step-up' existing routines (Haynes, 1976) but further work is needed to verify this.

2.3.3 Duration of treatment

Most authoritative reviews of the literature show that adherence rates often decline with longer duration of treatment and nonadherence is more prevalent if the treatment is prophylactic or is not perceived to produce symptomatic benefit (Meichenbaum and Turk, 1987; Haynes et al. 1979). Much of this evidence comes from prospective studies in which adherence to newly prescribed regimens is assessed at regular time intervals. A more recent study of adherence over a 12 week period following initiation of anti-depressant therapy suggests that the type of nonadherence may vary with duration of treatment: early nonadherence was characterised by discontinuation of the treatment and latter nonadherence characterised by the tendency of the patient to vary the dosage of their medication (Myers and Branthwaite, 1992). We currently know little about how patterns of adherence might change over the course of treatment.

2.3.4 Cost of treatment

It is thought that some patients may fail to redeem prescriptions because they cannot afford to pay the prescription charge. In the UK over half the population are exempt from prescription charges (McGavock, 1996). One study of primary nonadherence involving nearly 5,000 patients attending a large general practice in England showed that non-exempt patients redeemed significantly less prescriptions than those who were exempt from charges (33% vs 17%). This suggests that cost may be a barrier to adherence for certain patients/medications (Beardon et al. 1993). Others have suggested that increases in prescription costs may lead to greater primary nonadherence and even deter patients from visiting their GP (McGavock, 1996; Ryan and Birch, 1991).

2.4 Patient characteristics as determinants of adherence

2.4.1 Sociodemographic characteristics

Meichenbaum and Turk in their extensive review of the early adherence literature conclude that: 'the search for stable factors which comprise the nonadherent uncooperative, or chronic defaulter patient has met with little success' (Meichenbaum and Turk, 1987). A systematic review of 185 studies failed to identify stable socio-demographic characteristics which were consistently associated with sub-optimal adherence (Sackett and Haynes, 1976) No clear relationship emerged between race, gender, educational experience, intelligence, marital status, occupational status, income and ethnic or cultural

background and adherence behaviours. The only consistent finding was that nonadherence was associated with extremes of age. Meichenbaum and Turk (1987) suggest that this may be because the very young are more averse to bad tasting medicine and the very old are more susceptible to forgetfulness or self-neglect. However, a number of recent studies which have compared adherence rates over a fairly wide range of ages, suggest that the commonly held view that elderly patients are less adherent than their younger counterparts is misguided (Bosley et al. 1995; Frazier et al. 1994; Lorenc and Branthwaite, 1993; Sherbourne et al. 1992). Indeed there is growing evidence to suggest that adherence rates are often lower in younger than in older adults (Daniels et al. 1994; Sherbourne et al. 1992; Lorenc and Branthwaite, 1993; DiMatteo et al. 1993; Frazier et al. 1994). Recent research suggests that the explanation for this finding may lie in age-related differences in attitudes to health maintenance and management of illness (Leventhal E, A and Crouch, 1996 in press). The relationship between age and medication adherence is discussed in more detail in Chapter 7. There is little evidence that adherence behaviours can be explained in terms of trait personality characteristics (Bosley et al. 1995; McKim et al. 1990; Becker, 1979). Becker, (1979) pointed out that a socio-demographic/personality trait approach to adherence is fundamentally limited. Even if stable associations existed, they would serve to identify certain "at risk" groups to facilitate targeting of interventions but could do little to inform the type or content of interventions. Furthermore, sociodemographic characteristics and personality traits are not generally amenable to change and therefore present few opportunities for interventions to enhance adherence.

In practice, the idea that stable sociodemographic or dispositional characteristics are the sole determinants of adherence is discredited by evidence that an individual's levels of adherence may vary widely over time and between different aspects of the treatment regimen (Hilbrands et al. 1995; Cleary et al. 1995; Kruse and Weber, 1990; Rudd et al. 1989). This is not to say that sociodemographic or dispositional characteristics are irrelevant. Rather it would seem that associations with adherence may be indirect and best explained by the influence of sociodemographic and dispositional characterises on other relevant parameters such as illness-related cognitions (Leventhal et al. 1993; Leventhal and Crouch, in press).

The lack of evidence for stable associations between sociodemographic / personality factors, coupled with the inherent limitations of this approach has stimulated researchers to switch attention to patient characteristics which might be amenable to change such as

degree of understanding, knowledge and satisfaction and physical ability to manage the medication.

2.4.2 Medication knowledge and adherence

Many patients lack basic knowledge about their medication (Cartwright, 1994; Eagleton et al. 1993; al Mahdy and Seymour, 1990). However, the relationship between a patient's knowledge of their medication regimen and their adherence to it is by no means simple or clear-cut. In his classic, systematic review of the adherence literature, Haynes concluded that, although 12 studies had demonstrated a positive association between knowledge and adherence, at least twice as many, more methodologically sound studies, had failed to demonstrate a link (Haynes, 1976). Studies conducted since then generally reinforce the view that that associations between knowledge and adherence are at best small and inconsistent (Lee et al. 1992; Eagleton et al. 1993) and that enhancing knowledge does not necessarily improve adherence (George et al. 1983; Haynes et al. 1978).

Another reason for inconstancies in association between knowledge and adherence is that medication knowledge is not a unitary concept, but rather comprises different knowledge components. This is illustrated by the work of Ascione and colleagues (1986), who found wide intra and inter-patient variations in level of knowledge about three aspects of medication among 187 ambulatory cardiovascular patients. Patients knew most about the purpose of the medication and how to take it. Fewer patients knew what to do if they missed a dose and only a small minority could identify the common side-effects associated with their treatment. Thus the observed inconsistencies in relations between medication knowledge and adherence may be partially explained by variations in the way in which medication knowledge is conceptualised and measured.

Why do many patients have such poor knowledge about their medication? At least part of the answer to this question lies with patients' understanding and recall of information provided by HCPs. Addressing these issues extends the scope of adherence research to include the role of the physician (DiMatteo and DiNicola, 1982) and HCP-Patient interactions (Ley, 1988).

2.5 HCP-Patient interactions as determinants of adherence

Patients do not always understand prescription instructions (Sarriff et al. 1992) and often forget considerable portions of what health care practitioners tell them (Weinman, 1987; Ley and Llewellyn, 1995). For example, one early study found that approximately 50% information provided by the doctor was forgotten within 5 minutes of leaving the surgery (Joyce, 1969). It is well recognised that many patients have a poor understanding of terminology which is often used by doctors in communicating details about illness (Weinman, 1987; Boyle, 1970) and medication (Sarriff et al. 1992). Consequently, many patients have little or no understanding of the details of their medication regimen (Cleary et al. 1995; Eagleton et al. 1993; Lee et al. 1992).

The percentages of information recalled across a range of studies involving patients from several diagnostic groups in various health care settings are presented in Table 2.1. A detailed analysis of the influence of characteristics of the patient and material presented on recall rates is beyond the scope of this thesis. However, Ley (1995) has recently summarised the findings of research in this area.

Table 2.1 Summary of studies of recall of medical information (from Ley, 1995)

Type of subject	Number of samples	Mean percentage recalled	Range
Hospital patients	8	54	40-70
General practice patients	6	65	50-88
Patients given informed consent materials	9	47	29-72

Further insights into the complex interaction between knowledge and adherence may arise from consideration of the differential impact of medication knowledge on *passive* and *active* adherence. For instance, if a patient is motivated to take their medication then poor understanding or recall of how and when to use it could pose a significant barrier to following the instructions and result in passive nonadherence. Conversely, some patients may decide not to follow medication instructions (active nonadherence), despite being well-informed.

There is increasing interest in the role of patient satisfaction as a mediator between information provision, recall and adherence. Surveys conducted over the last 20 years or

so suggest that many patients are dissatisfied with aspects of consultations with HCPs and the amount of information offered to them about their illness and treatment (Cartwright, 1967; Hall et al. 1988; Ley, 1982; Gibbs and George, 1990). In a national UK survey of patients' satisfaction with medicines information received, an average of over 70% of subjects wanted more information than they were given (Gibbs and George, 1990). Dissatisfaction with attributes of the practitioner or the amount of information and explanation provided may act as a barrier to adherence by making the patient less motivated towards the treatment (Hall et al. 1988). Ley has summarised the findings of studies exploring links between understanding, recall, satisfaction and adherence in the form of a correlational diagram reproduced in Figure 2.1 (Ley and Llewellyn, 1995).

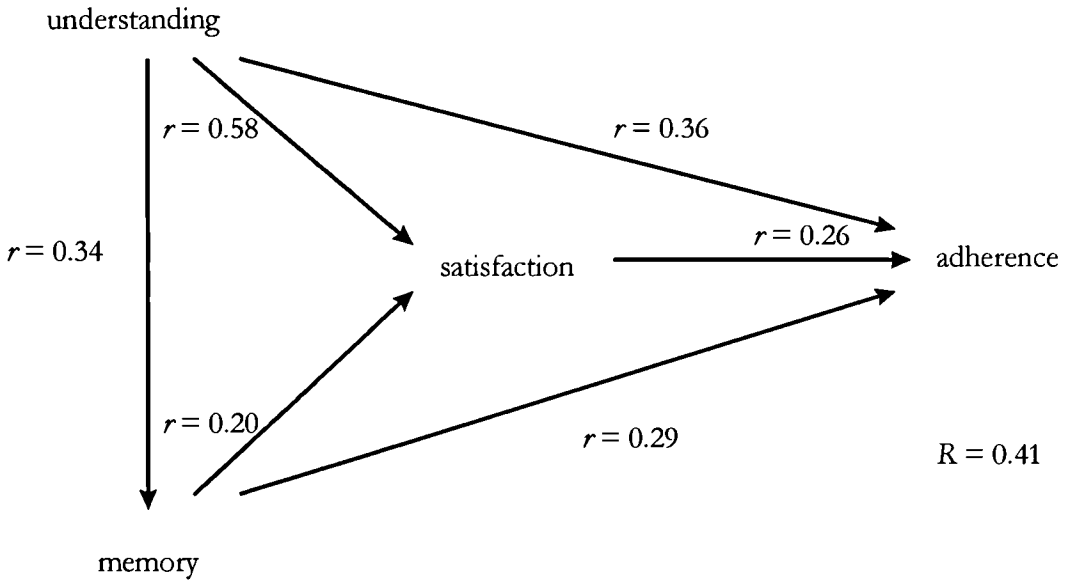


Figure 2.1 Relationships between understanding, memory, satisfaction and compliance (Ley, 1995)

More recent studies have attempted to relate patient satisfaction to the degree to which patient expectations about specific aspects of the consultation were fulfilled (Williams et al. 1995; Lassen, 1991). In a study involving 504 patients of 25 GPs in 10 London practices; patient expectations - defined in terms of needs, requests and desires, prior to seeing the doctor - and their fulfilment were assessed using validated questionnaires. Patients were generally much more eager to obtain an 'explanation of their problem' than they were to obtain 'support' or 'tests and diagnosis' and the degree to which their expectations were met was predictive of satisfaction with the encounter.

Further insight into the importance of addressing patients needs for clear explanations of their illness and treatment is provided by the Medical Outcomes Study - a large study of how patients fare with health care in the USA (Stewart and Ware, 1992). One aim of this study was to examine the influence of physician's characteristics on patient adherence to a range of treatments. In a cohort of over 8,000 patients, reported medication adherence at 2 years was related to reported medication adherence at baseline and to the tendency of the physician to report that they saw a greater number of patients per week, and arranged a specific follow up appointment. It is interesting that the socio-demographic characterises of patients and doctors had no influence on adherence and that adherence to one aspect of the treatment (e.g. medication) did not predict adherence to any other (e.g. diet, exercise). The authors hypothesise that adherence was stimulated by scheduling frequent follow up visits in which the patients' experience with medication could be monitored.

A further aspect of patient satisfaction in relation to medication use is the extent to which their desire to be involved in the decision to prescribe is fulfilled. More studies are needed to establish whether the patients' degree of perceived empowerment within the prescribing decision is correlated with adherence (McCrea et al. 1993).

2.6 Interventions to enhance medication adherence

A cursory overview of published studies confirms Rudd's view that 'the arena of interventions to enhance medication taking remains is an important barometer of assumptions and prejudices about compliance itself' (Rudd, 1993). The tendency has been to base interventions around single specific determinants of adherence which the investigators believe to be salient. Thus interventions can be grouped into two broad categories, based on the antecedents of nonadherence which they are designed to address.
Behavioural interventions: attempt to reduce the barriers to adherence by making the regimen more convenient or less costly or by issuing the patient with reminders or cues.
Educational interventions are based on the principle that patients do not adhere to treatment because they have not understood or do not recall what is expected of them. Intervention focuses on redressing this by providing clear instructions, often in the form of printed leaflets to aid recall.
There are several examples of studies, based on one or both of these approaches which have enhanced adherence. For example reducing the number of daily doses (Baird et al. 1984) or altering the packaging or formulation of the medication to improve access (Murray et al. 1993) has produced moderate improvements in adherence in controlled

trials. Tailoring the medication regimen to fit into the patients' daily routine seems to be particularly effective (Logan et al. 1981). Other studies have focused on the provision of educational materials designed to enhance patients' knowledge about their regimen. Augmenting the basic information routinely provided on the medication label with written information about what the medicine is for, common side effects and what to do if a dose is forgotten improves satisfaction (Gibbs et al. 1990) but the effect of enhanced information on adherence is inconsistent with some studies showing benefit and others finding little effect (George et al. 1983; Weinman, 1990). Interestingly, George and colleagues (1983) noted a differential effect of information on adherence to particular medication. Information was associated with higher adherence to penicillin antibiotics but lower adherence to non-steroidal anti-inflammatory drugs (NSAIDs). Interventions using behavioural and educational approaches in combination have also been shown to enhance adherence (Lowe et al. 1995; Raynor et al. 1993; Logan et al. 1981) whereas others have had no effect (Sackett et al. 1975).

On reviewing the 'adherence interventions literature' it quickly becomes apparent that although one finds particular interventions which appear to have improved adherence in specific situations, no single intervention seems to stand out as being consistently effective. In a recent systematic review of this literature, Haynes and colleagues (1996) commented that the majority of interventions are limited in scope and that most of the strategies evaluated using rigorous controlled clinical trial methodologies were 'not very effective, despite the amount of effort and resources they consumed'.

Does this mean then that non-adherence is an insurmountable problem? Before concluding that this rather bleak assessment is true, we need to ask why studies have failed to identify interventions which are consistently effective. Broadly speaking, failure could be due to the fact that the intervention was inadequate or that the study was flawed. Although, the former applies in many cases, the latter is also a key factor. Several reviewers have identified significant flaws in the design of studies assessing adherence interventions and these are summarised in Table 2.2. The scale of the problem is illustrated by a recent systematic review in which only 13 of over 1500 papers citations and abstracts screened met the criteria for detailed review (Haynes et al. 1996). However, even methodologically sound studies 'provided little evidence that medical adherence can be improved consistently within the resources usually available in clinical settings'.

Table 2.2 Summary of common methodological flaws in studies assessing interventions to enhance medication adherence

Common methodological flaws
• Intervention is not clearly described or individual components not detailed
• Not randomised controlled trials
• No information on base-line adherence
• Lack of 'attention placebo means that it is difficult to distinguish between the specific effect of intervention and those arising from increased attention alone.
• Short term follow up
• Numbers are too low so that study lacks statistical power
• Treatment outcome not measured and hence it is difficult to judge the whether changes in adherence benefited the patient

The discovery of a single intervention which is effective in all situations is something of an ' adherence Holy Grail' but the fact that it has not yet been found should not surprise us. The search seems to rest on an implicit assumption that adherence is a unitary phenomenon. However, it is clearly multifactorial with a large range of determinants. One reason why the success of adherence interventions does not seem to be generalisable is that adherence behaviours are not generalisable. It is likely that the salience of particular determinants will vary between individuals and in the same individual across treatments and over time. A further complication is that nonadherent behaviour may be the intentional result of an active decision by the patient (Cooper et al. 1982). Thus, an intervention which is effective in some situations (e.g. reminding the patient who forgets) may be ineffective in another (e.g. if the patient avoids taking the medication because of unpleasant side-effects).

The multifactorial nature of adherence and the fact that nonadherence is often volitional has led to a shift in the conceptualisation of adherence and a change in the focus of research. It is now recognised that adherence is best thought of as a *state*, rather than a *trait* characteristic. Individual patients may adhere to some aspects of their treatment and not others and adherence rates may vary over time. Interventions geared to making the patient more effective at following the prescribed instructions are unlikely to work if the patient has decided not to take a particular medication or if taking it is perceived as unimportant. Consequently the emphasis of adherence research over the last decade or so has moved away from attempts to identify stable trait factors which characterise the nonadherent patient to achieving a greater understanding of how and why patients decide to take some treatments and not others.

CHAPTER 3

A review of social cognition models and self-regulatory theory approaches to medication taking

Social Cognition Models (SCMs) are theoretical approaches to understanding health-related behaviour. They share a common assumption that attitudes and beliefs are major determinants of behaviour. Many use an expectancy-value approach in which behaviour in response to health threats or messages arises from an active decision based on two types of cognition. These are *expectancies* or beliefs about the probability that a specific action (e.g. taking medication) will lead to a set of outcomes (e.g. improved health) and the subjective *value* placed on them. Some, such as the health belief model (HBM) have been specifically developed to explain health-related behaviours, others, such as the theory of reasoned action (TRA) are derived from general models of behaviour. In this chapter, I will describe several SCMs. Although, there is some overlap between models, for the sake of simplicity, each model will be discussed individually. This will be followed by a summary of the contribution of each model to our understanding of medication adherence derived from a critical review of published studies.

3.1 The Health Belief Model (HBM) (Rosenstock, 1974)

This model was developed to explain why people failed to take up disease prevention measures or screening tests before the onset of symptoms (Rosenstock, 1974).The original model proposed that the likelihood of someone carrying out a particular health behaviour (eg attending for screening) was a function of their personal beliefs about the perceived *threat* of the disease and an assessment of the *risk/benefits* of the recommended course of action. Perceived threat, or vulnerability, is derived from beliefs about the perceived *seriousness* of the threat and the individuals perceived *susceptibility* to it. The individual then weighs up the perceived *benefits* of an action (e.g. taking medication might ease symptoms) against the perceived *barriers* to the action (e.g. fear of side-effects or costs of the treatment.). A further component was added by Becker and Maiman (1975) which makes the model more applicable to adherence to treatment regimens. They stipulated that a cue to action or stimulus must occur to trigger cognitions about

vulnerability and benefits/risks of action. This model is shown in Figure 3.1. Thus, the HBM predicts that the likelihood of action is increased if the perceived threat of the disease is high and if the benefits of behaviour are thought to outweigh the barriers and if certain cues are in place.

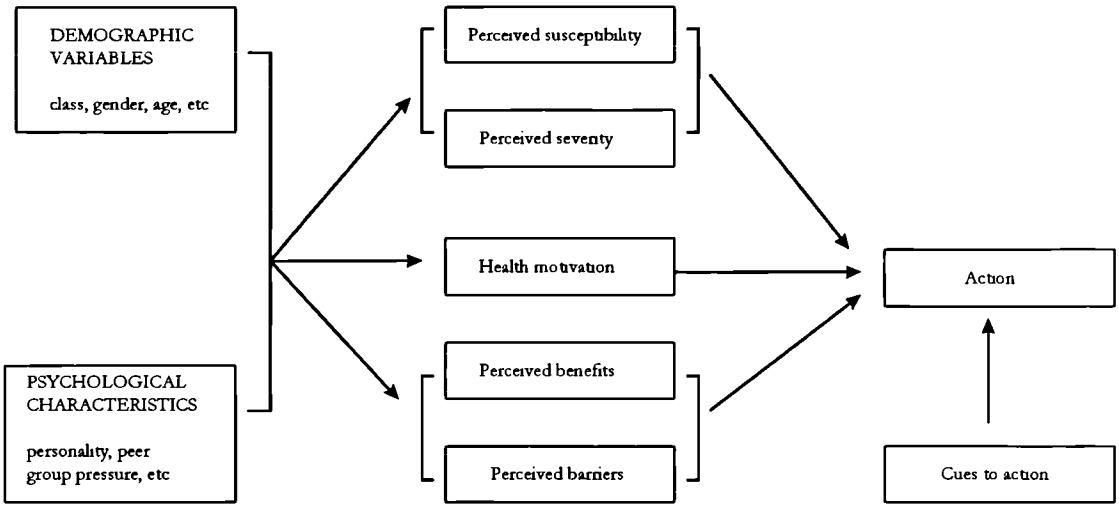


Figure 3.1 The health belief model (adapted from Sheeran and Abraham, 1996)

The original HBM is directed towards the individual's desire to avoid a specific disease threat. Several revisions have been made to this original model by including modifications as listed below:

- General health motivations which are seen as fairly non-specific personal attributes which are stable across situation.
- Resusceptibility to an illness previously contacted and currently under consideration.
- General orientation towards medicine.
- Characteristics of the doctor-patient relationship.

The HBM has also been modified for use in children by inclusion of certain developmental factors which reflect the changing personal, social and environmental influences which are pertinent to children (Bush and Iannotti, 1990).

Empirical support for the HBM in predicting health-related behaviours is equivocal (Marteau, 1995). In support of the model, Janz and Becker (Janz and Becker, 1984),

conclude that the majority of 46 studies of the HBM conducted prior to 1984 found statistically significant relationships between barriers (89%), susceptibility (81%), benefits (78%) and severity (65%) and health behaviours. Although, these data indicate that the components of the model are related to behaviour, they should be interpreted with caution. The percentages shown in brackets refer to the percentage of studies, in which statistically significant correlations between a particular HBM component and health-related behaviour had been found. However, this provides limited information about the usefulness of the model in predicting behaviour. It gives little information about effect size or about whether behaviour was influenced by an interaction between variables as predicated by the model, or just by isolated components of the model.

The HBM or its components have been utilised in a large number of research studies investigating health-related behaviours. However, it is difficult to draw firm conclusions about the viability of the model because of differences in the way in which it has been operationalised and applied across studies. In the main, the HBM seems to work best when it is used as originally intended as a predictive model for preventative behaviours (Janz and Becker, 1984). A meta analysis of studies relating the HBM to preventative health behaviours found that on average 24% of variations in behaviour was accounted for by combined HBM variables (Zimmerman and Vernberg, 1994). Although this may seem a relatively small effect, Abraham and Sheeran (in press) point out that "explaining 25% of variance corresponds to a potential success rate increase from 25% to 75%". They illustrate this effect with a hypothetical example in which 25% of a target population currently carry out a behaviour. If an interaction based on the HBM was successful in changing relevant cognitions in the 75% of the population who do not currently engage in the behaviour, it would result in a behaviour change in 75% of the population.

3.2 The HBM applied to medication adherence

The HBM has also been applied to medication taking in acute and chronic conditions. However, evaluating the value of the HBM in explaining adherence to medication is hampered by the fact that relatively few studies have operationalised the model in its entirety. Researchers tend to take a 'pick and mix' approach using only selected components of the HBM, usually in combination with variables derived from other theoretical approaches (Newell et al. 1986; Barnhoorn and Adriaanse, 1992). Methodological flaws add another dimension of difficulty. Failure of the model to predict adherence might be due to the use of an inappropriate methodology as much as to

deficiencies in the model itself. This point is best illustrated by a more detailed evaluation of the available studies which have used the HBM in the context of medication adherence.

Given the origin of the HBM as a theoretical interpretation of the antecedents of preventative health-behaviours, one might imagine that it would be most usefully be applied in situations where medication is prescribed as prophylaxis. Testing the predictive power of the model, would be best achieved using a prospective design in which cognitions at time 1 are related to adherence behaviour at time 2. The HBM might therefore be particularly suitable for investigating adherence in hypertension and several studies have addressed this.

3.2.1 Hypertension

An example of this was Taylor (1979) in a prospective involving a cohort of hypertensive Canadian steel-workers selected from a larger intervention study (Sackett et al. 1975). Health beliefs were measured prior to diagnosis (n=230) and at 6 and 12 month follow ups (n=128). Medication adherence was assessed by pill count and self-report during the follow up visits. None of the HBM measures at baseline correlated with adherence at 6 or 12 months. However, for the sample of patients who received a diagnosis of hypertension, several HBM variables measured at 6 months were predictive of adherence at 12 months. Medication adherence, assessed respectively by pill count and self-report was correlated with drug safety (r=0.27,0.23), perceived seriousness of hypertension (r=0.32,0.20) and perceived degree of social dependency related to hypertension (r=0.23,0.21). Linear regression analysis showed that these cognitive variables explained a total of 15% variance in pill counts and 9% variance in self-reported adherence. Several methodological limitations reduce the generalisability of these findings. It is unclear why the authors chose not elicit HBM variables shortly after diagnosis, rather than before. Receiving the diagnosis is likely to influence HBM cognitions, and might itself act as a behavioural cue. The survey was a sub-set of a larger intervention study in which an educational and physician follow up intervention was compared against standard care. The authors do not appear to have controlled for the intervention in their findings and so it is not possible to judge whether receipt of the intervention confounded the effect of HBM variables on adherence. Finally the authors provide little information of how the HBM constructs were operationalised or measured, so that it is difficult to judge the validity of their findings.

A further prospective study of the HBM in hypertension was conducted by Inui and colleagues (1976). This was essentially a controlled trial of a physician-based intervention to improve patient adherence to medication. Physicians in the intervention group were given tutorials on how to communicate health information to patients about their illness, based around the concepts of the HBM. To evaluate the intervention, medication adherence and blood pressure control of patients visiting these clinicians was compared, 7 days and 60 after clinic visits, with those attending control clinicians. Patients visiting clinicians in the intervention group were more adherent with better blood pressure control. This study represents one of the few cases where an intervention has been based specifically on the HBM. However, as a test of the validity of the HBM as a predictor of medication adherence it is spectacularly flawed. Chiefly, differences in adherence or outcome between groups cannot be attributed to differences in HBM related cognitions of patients since these were not measured. Rather one is left to assume that implementation of the HBM based intervention influenced physician attitude and behaviour which in turn influenced the attitudes and behaviour of the patients.

Nelson and colleagues (1978) in a study of 142 patients with hypertension, found a statistically significant association between reported medication adherence and two HBM components: 'perceived severity of own hypertension' and 'perceived experience of medication side-effects'. The perceived benefits of treatment, conceptualised as perceived efficacy of medication, did not influence reported medication adherence. Although this study implies that certain cognitions, specified within the HBM, may be involved in adherence decisions, a number of methodological problems alert us to interpret these results cautiously. First, there are problems with the way in which the key dependent and independent variables were operationalised. Adherence was assessed by interview in which patients were asked to detail the frequency of missed doses over the previous 28 day period. On the basis of their response participants were classed as adherent (none missed) or nonadherent (one or more doses missed). Dichotomising the data in this way, may not represent the most clinically valid interpretation of adherence and results in loss of information provided by the interval data collected. The investigation also interpreted the HBM variables rather loosely, including medication side effects as a 'modifying factor', rather than as a 'barrier' as stipulated (Janz and Becker, 1984), and by adding new variables such 'priority of health in life'. A further drawback, is that the cross-sectional design of the study hampers the attribution of causality. This point is discussed in more detail later.

3.2.2 Renal disease

The HBM has been used to investigate treatment adherence in patients with End Stage Renal Failure in two studies. Cummings (1981) and colleagues found that self-reported adherence to dietary recommendations and medication was correlated with *susceptibility*, *benefit* and *barriers* in a sample of 116 patients receiving haemodialysis. However, this study was also part of a larger intervention study and was cross-sectional in design , so that it is difficult to judge whether the effect of beliefs on adherence was causative or reactive. The problems associated with the use of the HBM and other expectancy-value models in cross sectional studies is illustrated by another study involving haemodialysis recipients (Hartman and Becker, 1978). All HBM dimensions correlated with 'objective indicators' of adherence (serum phosphate, serum potassium and inter-dialysis weight gain) to medication and diet/fluid restrictions in a cross-sectional study of 50 haemodialysis recipients. However, the correlation between adherence and '*susceptibility*' was negative. This is contrary to the HBM which predicts that high susceptibility scores would stimulate higher adherence. The explanation for this apparent anomaly might lie in the fact that these data are cross-sectional and that the perception of low susceptibility to future adverse effects of the disease might be a consequence of high adherence ('I am following the doctor's advice and will therefore be protected'). The issue of causal relationships and predictive validity of SCMs will be dealt with in more detail later in this chapter.

3.2.3 Psychiatric illness

The HBM has also been applied to medication adherence among American psychiatric out-patients (Kelly et al. 1987). In this study (n=107), which is one of the few to adequately describe the psychometric properties and distribution of scores on the scales used to assess components of the model, HBM variables explained 20% of the variance in reported adherence. Although in this study, some of the individual components of the HBM were related to adherence, this does not constitute evidence that reported adherence was predicted by the HBM for several reasons. First the data are cross-sectional and so cannot be used to confirm the causal relationship between beliefs and behaviour stipulated within the HBM. Second, reported adherence was predicted by particular components, rather than by the model as a whole. *Barriers*, perceived *susceptibility* and *cues* made significant contributions to the variance in reported adherence but *severity* and *benefits* did not make a statistically significant contribution. In this study the items used to assess the various HBM components reflect its application to the self-management of a chronic illness rather than

to preventative health behaviours. *Susceptibility* was operationalised as the perceived risk of future hospitalisation and *barriers* as the perceived experience of medication side effects.

Other studies have also shown that adherence to medication prescribed for psychotic illness was related to patients perceptions of benefits and costs (Hogan et al. 1983; Ludwig et al. 1990). The model has been applied in its entirety in only two studies in the psychiatric area. In contrast to Kelly and colleagues (1987), Pan and Tantam (1989) found no difference in health beliefs between adherent and non-adherent patients. In a recent well designed study of adherence to anti-psychotic medication Budd and colleagues (1996) found that certain HBM variables were related to adherence. Discriminant function analysis showed that non-adherent patients (defined as those who had failed to attend and/or refused medication for one third or more of all scheduled appointments) could be distinguished from adherent patients on the basis of *susceptibility*, *severity* and *benefits* dimension of the HBM but not on the basis of costs.

3.2.4 Diabetes

Browlee-Duffeck and colleagues (1987) applied the HBM to insulin treated diabetic patients. Relations between HBM components, reported adherence and metabolic control were evaluated in younger (n= 54; mean age=18) and older (n=89; mean age =36) clinic samples. Adherence was indicated by a composite scale assessing medication usage, diet and monitoring and glycosylated haemoglobin results (G Hb) which provided an indication of blood glucose control over the preceding three months. Certain components of the HBM were related to the composite self-reported adherence scale in each of the samples studied. However, it is particularly interesting to note that the 'predictive components' differed considerably between samples. In the younger sample, perceived costs predicted 20% of the explained variance in reported adherence, with other HBM components adding a further 3%. In contrast, in the older sample, perceived benefits were much more strongly related to adherence explaining 17% of the variance with costs and barriers adding 5% and 2% respectively.

3.2.5 Conclusions

So what does the HBM contribute to our understanding of medication adherence? Methodological limitations in the way in which the model has been operationalised and applied in studies of medication taking prevent us from drawing firm conclusions. Common flaws in existing studies include the use of cross-sectional designs to test a predictive model, lack of explanation of how constructs were operationalised and validated and the presence of cofounders such as interventions. However, despite these limitations this work does further our understanding of medication adherence showing that medication adherence is related to certain cognitions. Adherence was typically predicted by various combinations of individual components rather than the precise interactions specified in the model. Although medication adherence cannot be completely explained by the HBM, there is evidence that some of the cognitions specified within the model influence to medication taking. The available evidence supports the notion that our understanding of medication adherence may be enhanced by examining patients' own ideas about their illness and confirms the limitations of sociodemographic variables as predictors. However, it also suggests that cognitive variables other than those specified in the HBM may also influence medication adherence.

Although several studies have demonstrated the value of interventions based on the HBM in facilitating health-related behaviours such as attending for medical check-ups (Haefner and Kirscht, 1970) or using emergency care facilities in an acute asthma attack (Jones et al. 1987) few studies have applied this model to interventions to enhance medication adherence.

3.3 The Theory of Reasoned Action

The HBM does not take account of social influences on behaviour or explain how perceived threat and the cost-benefit analysis are translated into action. Such issues are central to the theory of reasoned action (TRA) (Ajzen and Fishbein, 1980; Fishbein and Ajzen, 1975). The TRA was developed from research investigating relationships between attitudes and behaviour. It is not specific to health but has been widely used in this context (Stroebe and Stroebe, 1995). The central tenets of the TRA are that the formation of *intentions* precedes and predicts behaviour and that intentions are determined by *attitudes*

towards the behaviour and *subjective norms* concerning the behaviour. Attitudes towards the behaviour are defined as the product of beliefs about the likely outcome (e.g. "Following the doctor's recommendations for using insulin will keep my diabetes under control") and the perceived value of the outcome (e.g. "Keeping my diabetes under control is important to me."). The person's subjective norm comprises beliefs regarding others views about the behaviour (e.g. "My partner wants me to follow the recommendations") and the motivation to support these views (e.g. "I wish to please my partner by following the recommendations").

3.4 Theory of Planned Behaviour (TPB)

Perceived behavioural control and perceived barriers have been added to the TRA to form the Theory of Planned Behaviour (TPB), shown in Figure 3.2 (Ajzen, 1985), and there is evidence that this improves predictions of intentions and behaviour in a wide variety of circumstances (Ajzen, 1991) including preventive health behaviours (Conner and Sparks, 1996).

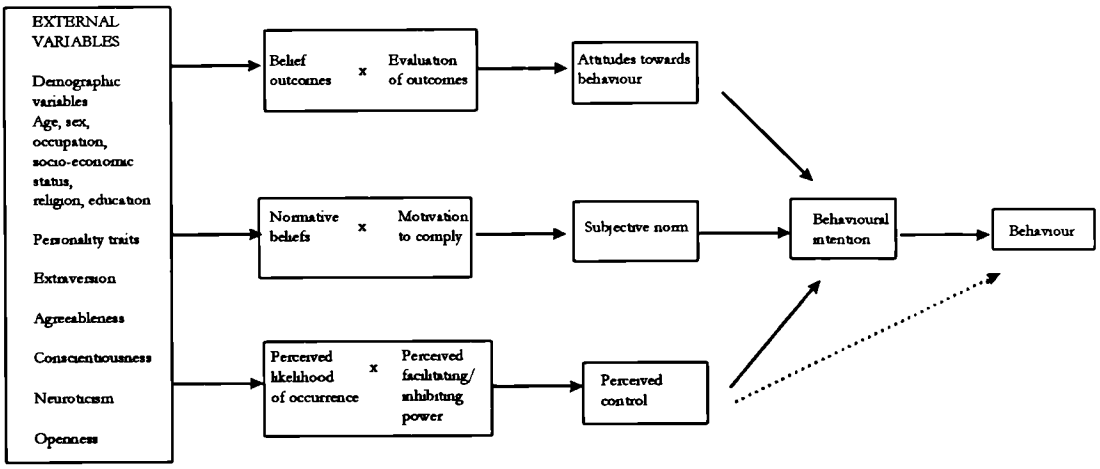


Figure 3.2 The theory of planned behaviour (TPB) (adapted from Conner and Sparks, 1996)

The TRA and TPB have been shown to be of value in predicting a range of health related behaviours including giving up smoking , engaging in an exercise programme, initiating a healthy diet and using a condom during sexual intercourse. In the main there is broad support for the assertion that behavioural intentions are influenced by attitudes and

subjective norms although the strength of the relationship between intentions and behaviour varies across studies and between behaviours (Eagly and Chaiken, 1993).

3.5 Application of the TRA and TPB to medication adherence

Although the TRA/TPB have been widely applied to preventative health behaviour, relatively few studies have used it to investigate medication adherence. These are reviewed below and have addressed medication prescribed for the treatment of urinary tract infections (Ried and Christensen, 1988), bipolar affective disorders (Cochran and Gitlin, 1988) and hypertension (Ried et al. 1985; Miller et al. 1992). Abraham and Sheeran (Abraham and Sheeran, 1996) have pointed out that key HBM variables such as perceived benefits, barriers and severity can be included as components of the attitude measure as they refer to the perceived likelihood and consequences of taking or not taking action. However, perceived personal susceptibility may need to be added to the TRA.

In an interesting study of adherence to antibiotic medication prescribed for acute urinary tract infections, Reid and Christensen (1988), used TRA variables together with four components of the HBM as the salient beliefs which underpin attitudes to taking the medication: perceived seriousness of medication nonadherence, perceived susceptibility to illness in general and medication adherence benefits and barriers. This study used a prospective design. Patients (n=107) who had been prescribed penicillin for their UTI completed questionnaires assessing salient beliefs about taking the medication. The authors also included a variable termed 'belief strength'. This was conceptualised as the perceived likelihood of experiencing UTI symptoms if medication were taken exactly as directed. Additional measures included patients' attitudes to the medication, assessed using a simple dichotomous scale, and their intention to take it. After 10 days, adherence to the regimen was assessed by patient self-report during a telephone interview. Multiple linear regression analysis showed that the HBM variables alone explained 10% of the variance in reported adherence and the remaining TRA variables explained an additional 19% of the variance. The most significant predictors of adherence, in terms of percentage variance explained, were; 'belief strength' (12%), barriers (8%), outcome evaluation (3%), and intention (3%). The 'belief strength' construct is a form of outcome expectancy. In view of its fairly strong predictive value it is interesting to consider the type of cognitions which might underpin this construct. which is presumably based on beliefs about the efficacy of the medication

This study concurs with other research suggesting that certain TRA and HBM constructs are prerequisites of medication taking . It is appropriate here to comment on the statistical methods used. Multivariate techniques such as multiple linear regression are a useful means of identifying which particular components within a model are predictive of behaviour. However, these techniques are less useful for assessing the value of the model as a whole. To do this one would need to assess the amount of variance in the dependent variable (behaviour) which can be explained by the interactions between the components specified in the theoretical model rather than by the individual components alone. Recent advances in path analysis techniques and the availability of statistical software packages such Lisrel® and EQS® have made it possible to evaluate the model as a whole (Dunn et al. 1993). The remaining studies which I will discuss under this heading have all applied path analysis to study the value of the TRA in predicting medication adherence.

In a cross-sectional study of predictors of intentions to take to anti-hypertensive medication, Ried and colleagues (1985), used path analysis to examine the value of the TRA. The model was operationalised in a similar way to that described above, using four HBM components (benefits and barriers of non-adherence and severity and susceptibility to the disease) as salient beliefs. A significant amount (37%) of the variance in intended adherence could be explained by the TRA if minor modifications were made. These were necessary because physician expectations had a direct effect on patients' attitudes and perceived susceptibility to the negative consequences of hypertension had a direct effect on intention. Physician expectations might contribute to the patients' subjective norms. Others have suggested that health professionals' beliefs may have an important influence on patients' beliefs and behaviours (Marteau, 1995), and that perceived susceptibility may need to be added to TRA conceptions independently of the attitude construct (Abraham and Sheeran, 1996).

A direct relationship between normative beliefs and attitude was also noted by Cochran and Gitlin (1988) in their application of the TRA to reported lithium adherence in patients with bipolar disorders. In this cross-sectional postal questionnaire survey of 48 lithium outpatients, 53% of the variance in reported adherence was explained by a modified TRA. In this model patients' attitudes and intentions, and hence adherence, were much more strongly influenced by the perceived views of *significant others* such as family doctors and friends, than by their own beliefs about the treatment. Patients' own beliefs did not directly influence behavioural attitudes or intentions.

Further empirical support for the TRA comes from another study of adherence to treatment recommendations in 47 patients with hypertension (Ried et al. 1985). Path analysis showed that TRA variables explained significant amounts of variance in reported adherence to diet (28%), smoking cessation (53%), physical exercise (37%), stress avoidance (11%) and medication taking (33%). Modifications to the TRA were necessary in most cases. For example, in models predicting dietary and smoking adherence, perceived beliefs of others had a direct influence on patients attitudes. For medication taking, attitudes and subjective norms had a direct influence on reported adherence which did not operate via intentions. A possible explanation for this anomaly lies in the way in which medication adherence was assessed. For all other behaviours patients' self reports were corroborated by their spouses. However, in the case of medication adherence, patients' reports were only weakly correlated with their spouses (r=0.23). It is therefore possible that reported adherence was subjected to self-presentational bias and is more closely related to patients' intentions rather than to their actual behaviour which was more accurately reported by their spouses.

A further possible problem with cross-sectional studies of this type is that of response bias. Budd and Spencer (1987) have cautioned against questionnaire based studies of the TRA. They argue that the TRA forms part of a 'intuitive lay psychology of intention' and that people filling out questionnaires assessing TRA components will attempt to create consistency between their responses, so appearing to validate the model. An opposing view is that the TRA is part of our intuitive model of intention <u>because</u> it reflects real psychological processes and fundamental interactions between the way in which people think and behave.

Few studies have applied this model to medication taking, although Hounsa and colleagues (1993) found the TPB useful in predicting African mothers intentions to adhere to recommendation for using oral rehydration therapy (ORT) for the treatment of their children's' diarrhoea. In this study 40% of the variance in adherence intentions was predicted by the perceived consequences of using ORT, perceived barriers to use and ease of access to health care services.

The studies described above provide tentative empirical support for the utility of TRA and TPB concepts in explaining medication adherence. However, it is clear that, as with the HBM, medication taking behaviour is not often explained by the precise interaction

between variables specified in the models. Rather the evidence suggests that, although many of the constructs specified in the TRA and HBM are prerequisites for medication adherence the relative importance of individual constructs and the interactions between them may vary considerably in different contexts. While expectancy-value models such as the HBM and TRA attempt to explain health behaviours in term of the nature of interactions between cognitions, a different approach has focused on identifying the types of cognitions which influence behaviour. This approach has drawn attention to the role of attributions, and control and efficacy beliefs as determinants of health behaviour.

3.6 Control beliefs

The concept of perceived control was applied to health by Wallston and colleagues (1978) who developed a measure of *health specific locus of control* (HLOC). This categorised people according to whether they attributed control over their health to internal or external factors. Later this measure was revised and extended to form the multidimensional health locus of control (MHLOC) scale (Wallston et al. 1978), since research with patients indicated that control beliefs should be assigned to three separate unipolar scales called internal, chance and *powerful others*.(Levenson, 1973a; Levenson, 1973b). There is some evidence that HLOC beliefs are predictive of certain health behaviours. For example people with an internal HLOC were more likely to be successful in seeking out information on health issues or reducing smoking than those with an external locus of control (Wallston and Wallston, 1982). However, the relationship between measures of locus of control over health in general and specific health behaviours is fairly weak. For this reason there has recently been a move away from the idea that individuals have a general perception of control over all aspects of health. Instead, research has focused on the assessment of perceived control over specific aspects of health or illness such as control of diabetes (Bradley et al. 1990), giving up smoking (Georgiou and Bradley, 1992), aspects of dental health (Beck, 1980) and other measures recently reviewed by Furnham and Steele (1993).

3.6.1 Empirical investigation of the role of control beliefs in medication adherence

The main application of the locus of control (LOC) concept to medicine taking has been to explain patients' desire for involvement in decisions (Wallston et al. 1991), choice of treatment options (Bradley et al. 1987) and usage of patient controlled infusion devises for administering medication (Reynaert et al. 1995)
Empirical studies investigating the role of LOC beliefs in medication adherence appear to be inconclusive. Some studies have found no association between control beliefs and adherence and in studies where associations were found, there is little consistency in the type of control which is associated with adherence. However, an interesting pattern can be discerned in these apparently anomalous findings.

Studies have failed to demonstrate significant interactions between peoples' beliefs about control over their health in general (MHLOC) and adherence to medication in several situations including affective disorders (Harvey and Peet, 1991; Harvey, 1992), renal transplantation (Frazier et al. 1994; Kiley et al. 1993) and in predicting intended adherence to an imaginary regimen in a study involving college students (McCallum et al. 1988).

However, the use of disease specific measures for assessing LOC improves the utility of this construct in explaining medication related behaviour. For example, patients with high scores on the *powerful others* dimension of a diabetic specific LOC scale were more likely to accept a treatment option which they perceived to be a 'high-tech' method of controlling their diabetes (Bradley et al. 1987). A further study showed that diabetic patients who were receiving conventional insulin treatment had lower scores on the *powerful others* dimension- but not *internality*- than those who were using an intensified treatment regimen or continuous sub-cutaneous insulin infusion. Both the latter regimens require the patent to play a much more active role in their own treatment (Kohlman et al. 1993). It is interesting to note that patients receiving conventional treatment were older and that other studies have shown that older patients tend to score more highly on the *powerful-others* dimension (Lachman, 1986; Lumpkin, 1986).

An interesting example of where the MHLC construct may be salient is that of patient controlled analgesia (PCA. In two studies, patients with high *internality* and low *powerful-*

others scores on the MHLC scale were more satisfied with this treatment, to report less pain and use less medication (Johnson et al. 1989; Reynaert et al. 1995). One interpretation of these findings is that patients who like to take control over their health, (high internality may be a marker for this), respond better in situations where they are given direct control over administration of analgesic. Alternatively it may be that the MHLOC scores are influenced by the patients' experience of PCA. PCA requires the patient to learn to use this fairly complicated technique. Those who subsequently find this difficult or are reluctant to administer their own medication for other reasons (e.g. fear of side-effects) may use the devise inappropriately, (e.g. by administering large infrequent doses rather than smaller regular ones as recommended) and so experience more pain. Patients in this situation may justifiably think that they have less control over their health than '*powerful others*' such as clinician.

The above studies, suggesting the utility of the HLC concept are somewhat atypical, as there is little empirical support for the LOC concept as a predictor of global indices of preventative health behaviour (Norman and Bennett, 1996). The failure of generalised control beliefs is consistent with Ajzen's point that specific measures are likely to be better predictors of specific behaviours, as people might hold different control beliefs for different behaviours (Ajzen and Fishbein, 1980). However, generalised control beliefs may be more important in relatively novel situations as is illustrated by the PCA studies described above.

Application of the LOC construct to adherence to medication in chronic illness is fraught with pitfalls. Much of the research involving HLC has focused on preventative behaviours, and has tended to individually asses relations between the target behaviour and each of the three LOC dimensions. This approach is derived from initial hypotheses that the degree of *internality* was particularly salient in determining readiness to engage in preventative health behaviours. However, Wallston (1992) suggests that an individual's LOC profile (i.e. a combined measure of relative standing on each of the three dimensions) is more important. This may be particularly true in the case of medication adherence where the 'ideal combination' might be sufficient *internality* to facilitate self-management of the regimen, combined with enough belief in *powerful others* (the clinician) to be motivated to follow the treatment recommendation. A further criticism of previous LOC research is that it has failed to incorporate an assessment of the *value* which the individual places on health in general or of carrying out a particular behaviour (Wallston, 1992; Lau et al. 1986). Adding a value component is implicit within social learning theory which stresses the interaction of *expectancies* (e.g. control beliefs) and *values*

As one focuses attention on a specific behaviour (e.g. adhering to a prescription for the regular use of a steroid inhaler), beliefs about the degree of control one has over the behaviour may be closely related to other expectancies such as beliefs about one's competency in being able to perform the behaviour.

3.7 Efficacy beliefs

Bandura (1986) has identified two types of efficacy beliefs as important: *outcome efficacy* which concerns beliefs about whether the behaviour will result in an effective outcome (e.g. "Taking medication will reduce my blood pressure and so prevent renal complications") and *self-efficacy,* which covers the individuals beliefs as to whether they will be able to carry out the behaviour (e.g. "I am confident that I will remember to take my medication every day"). Individuals may acquire their sense of self-efficacy from their assessment of the outcome of their own behaviour and the behaviour of others and feedback about their own behaviour which they receive from *significant others* (Bandura, 1986). Several studies have demonstrated a relationship between perceived self-efficacy and health-related behaviour such as giving up smoking (DiClemente et al. 1985) or carrying out an exercise program (Kaplan et al. 1984). Efficacy and control beliefs are strongly influenced by the individual's past experience of success or failure in specific health-related domains, and should not be confused with unrealistic optimism.

The inclusion of self-efficacy beliefs in social cognition models such as the HBM and TRA has been shown to enhance their ability to predict various preventative health behaviours (Schwarzer and Fuchs, 1996), and adherence to medication for tuberculosis, in a study conducted in India (Barnhoorn and Adriaanse, 1992). In general, self-efficacy beliefs are likely to be more salient for complex or difficult behaviours, such as giving up smoking, than for behaviours such as adherence to a simple medication regimen (Flanders and McNamara, 1984). Beliefs about control over health and self-efficacy and outcome-efficacies may be influenced by previous experience and other cognitions. In particular, they may depend on the person's beliefs about the cause of certain events and the extent to which their own behaviour was a key factor.

3.8 Causal beliefs

Attribution Theory (Turnquist et al. 1988) is concerned with the cognitive processes by which people explain the causes and outcomes of events. Its application is based on the notion that a fundamental response to adverse events such as illness is the search for explanations about cause and outcomes. Causal explanations are related to past experiences and can influence future response and adjustment to the illness.

Early research was mainly concerned with the extent of beliefs in *internal* (i.e. related to their own behaviour)or *external* causes (i.e. blaming fate or others). Recent work on attributional style and content has added further dimensions such as *stability* (i.e. whether the cause of the illness is long lasting or temporary), *globality* (i.e. global versus specific causes), *universality* (i.e. universal versus personal causal influences) and *controllability* (controllable versus uncontrollable influences). There is controversy over whether the specific nature of the attributions or the existence of attributions *per se* is most important. Some studies have found a positive association between the perceived severity of the illness and the number of causal attributions made by the patient (Affleck et al. 1987; Affleck et al. 1985). Others have found that adjustment to illness was related to the type of attribution, e.g. attributing cause to an environmental factor or to one's own behaviour (Wright et al. 1990; Brewin, 1984). A number of studies have investigated the specific application of attribution theory to health problems including end-stage renal disease ESRD (Wright et al. 1990), life-style changes among pre-operative coronary patients (Naea De Valle and Norman, 1992), depression, cancer (Taylor et al. 1984) and the perception of symptoms (Robbins and Kirmayer, 1991). It is clear that causal attributions are related to beliefs about cure and can influence the patient's behavioural response and adaptation to illness.

However, it has not been possible to identify one type of attribution which is universally adaptive. Certain attributions seem to adaptive in some situations but not others. For example, patients who attributed the cause of their myocardial infarction to uncontrollable factors such as fate were less likely to follow treatment recommendations. Additionally, people who believed that their heart attack was caused by changeable aspects of their own behaviour, such as smoking or eating had higher levels of adherence and better adjustment (Naea De Valle and Norman, 1992). There is evidence that beliefs about control affect whether attributions are adaptive or not. For example, people who attributed the cause of an illness to controllable influences (e.g. changeable aspects of their own behaviour) were

likely to adapt better than those whose causal attributions related to uncontrollable influences such as fixed personality traits (Tennen et al. 1986).

3.9 SCMs: contributions and limitations

What has research involving SCM contributed to our understanding of health behaviours in general and adherence to medication in particular? The social cognition approaches outlined above have identified a set of cognitions which seem to be prerequisites to the adoption of preventative health behaviours. Applied to medication-related behaviours they have identified cognitions which are germane to decisions about whether or not to take medication. In doing so they help to reframe adherence issues. Within a social cognition framework medication taking can be seen as a volitional act which is, to some extent, the result of a rational decision by the patient. This contrasts with other adherence research paradigms which, broadly speaking, tend to conceptualise nonadherence as a function of patient incompetence and clinicians' failure to enhance it, or as an unavoidable consequence of certain trait characteristics. Although limited in scope, SCM-related adherence research has opened the door to a broader conception of adherence. This recognises that medication adherence may reflect patients beliefs as well as their ability to comprehend, remember and follow instructions.

As well as highlighting the positive contribution of SCMs to our understanding of medication adherence, the research reviewed in this section has drawn attention to some of the limitations of these models. Marteau (1995) has pointed out that although SCM variables are often predictive of behaviour, the amount of variance explained by the models is sometimes small. She goes on to suggest that there are at least two possible explanations for this: the theories are invalid or that the theories are valid but have been inadequately tested. The above review of studies has identified several problems with the way in which SCMs have been applied to medicine taking, which, to some extent, mirror those identified in the broader applications of these models to health-related behaviours. Following Marteau (1995), the perceived limitations of SCMs can be addressed under two broad headings: those ariisng from methodological flaws in the way in which the models have been evaluated and those which can be attributed to the inherent limitations of SCMs as theoretical constructs.

3.9.1 Methodological limitations in the evaluation of SCMs

Operationalising the models The first limitation concerns the way in which the models have been operationalised. Early studies generally tended to pay scant regard to the description or psychometric evaluation of measures of SCM constructs. This has resulted in little or no consistency across studies making generalisation and comparison difficult. Moreover, when assessing the belief constructs specified by the models, researchers have tended to supply their version of 'model salient beliefs'. This may not reflect the patients' perspective and so may fail to identify those beliefs which are of key importance in the patient's decision (Leventhal, 1993). In a recent review, Norman and Conner (1996) make the point that most SCM studies use single-point determinations of behaviour and that assessing patterns of behaviour over time may be more worthwhile. They also make the plea for sounder psychometric evaluation of behaviour measures used in this context.

Methods of analysis Further limitations arise from the way in which data were analysed in many studies. Interactions between the cognitive and behavioural components of the model are often evaluated by univariate associations between individual components and particular behaviours. Where multivariate approaches are used, these tend to be regression analyses which identify those variables which contribute most to the variance in behaviour. These approaches are useful in identifying salient cognitions related to behaviour, but cannot characterise interactions between components or evaluate the model as a whole. To this end, there is a growing interest in path analysis and other techniques for modelling covariance (Dunn et al. 1993), which can be used to evaluate the degree to which a particular model 'fits' the data.

Determining causality A further issue concerns the timeframe for evaluating interactions between cognitions and behaviour. Many of the studies discussed above used cross-sectional designs. Although these designs may be sufficient to identify the cognitions which underlie behaviours (and are therefore useful) they cannot determine causality. In order to establish the causal relationship between a set of beliefs and behaviour, it is necessary to assess the degree to which current cognition correlates with future behaviour. This is key to the evaluation of predictive models and requires prospective research designs. However, applying these designs to SCM research is not without complication. A key issue is the time-gap between measurement of cognition and behaviour: too long and the link may have weakened. Today's behaviour may be more strongly influenced by today's cognitions rather than yesterdays.

3.9.2 Limitations of SCMs as explanatory models for health behaviours

Limitations to rationale decisions

One limitation of SCM is that they cannot easily explain health-related behaviour which is apparently irrational, such as the patient who delays seeking treatment for a large and visible tumour. Several studies investigating health behaviour have found future behaviour to be more strongly predicted by past behaviour than by cognitions specified with SCM such as the HBM and TRA. The influence of past behaviour has been noted in relation to diet, exercise and smoking (Mullen et al. 1987), recreational drug use (Bentler and Speckhart, 1979)and wearing a seat belt (Sutton and Eiser, 1990). So does this mean that cognition is irrelevant? In considering this question Norman and Connor (1996) draw attention to Ajzen's (1988) suggestion that the effects of past behaviour on future behaviour are mediated by variables included in the social cognition models. (Past experience of a behaviour may be an important source of expectations about and attitudes towards repeating the behaviour in the future (Ajzen, 1991)). Relationship between past and future behaviour may predominate because key cognitions have not been considered or have been poorly operationalised. Also, the relationship may be inflated by congruence between the methods of measuring past and future behaviour. A further explanation is that some health behaviours become habitual or routine (e.g. brushing ones teeth before bedtime) and are not always preceded by a rationale decision based on expectancy-value considerations.

Stages to health behaviour

The fact that cognitions and behaviour change over time has major implications for the validity of SCMs. First, the notion that interactions between behaviour and cognition may be dynamic rather than static, leads us to question when inter-relations specified in the model are particularly salient. It has been suggested that health behaviour may proceed in stages and that different cognitions may be more important in particular stages than in others: for example the thinking underlying *initiation* of a particular behaviours may be qualitative different from that involved in *maintenance* of the behaviour. Several stage models of health behaviour have been proposed in which health behaviours occur as the result of several stages of cognition. For example, the Transtheoretical Model (TM) (Prochaska and DiClemete, 1984) suggests that the maintenance of health behaviour occurs in five progressive stages of change: pre-contemplation, contemplation, preparation, action and maintenance. To date, the main application of the TM has been to understanding the stages changing addictive behaviours such as smoking and alcoholism

and there is as yet, little evidence to support its validity in health related behaviours such medication adherence. A similar model is the Health Action Process (HAP) (Schwarzer, 1992), which is shown in Figure 3.3. The model is separated into two broad stages: a motivational stage in which the individual forms an intention to act and an action phase in which the intention is translated into a behaviour. As can be seen from Figure 3.3, perceived self-efficacy is a crucial component having a direct influence on the formation of intentions, action plans and action control (maintenance strategies). In this model, perceptions of self-efficacy are thought to be more important than the expectancy-value considerations which precede them (Schwarzer and Fuchs, 1996). There has been little empirical evaluation of the model and it is too early to be able to judge the validity of the model with any certainty.

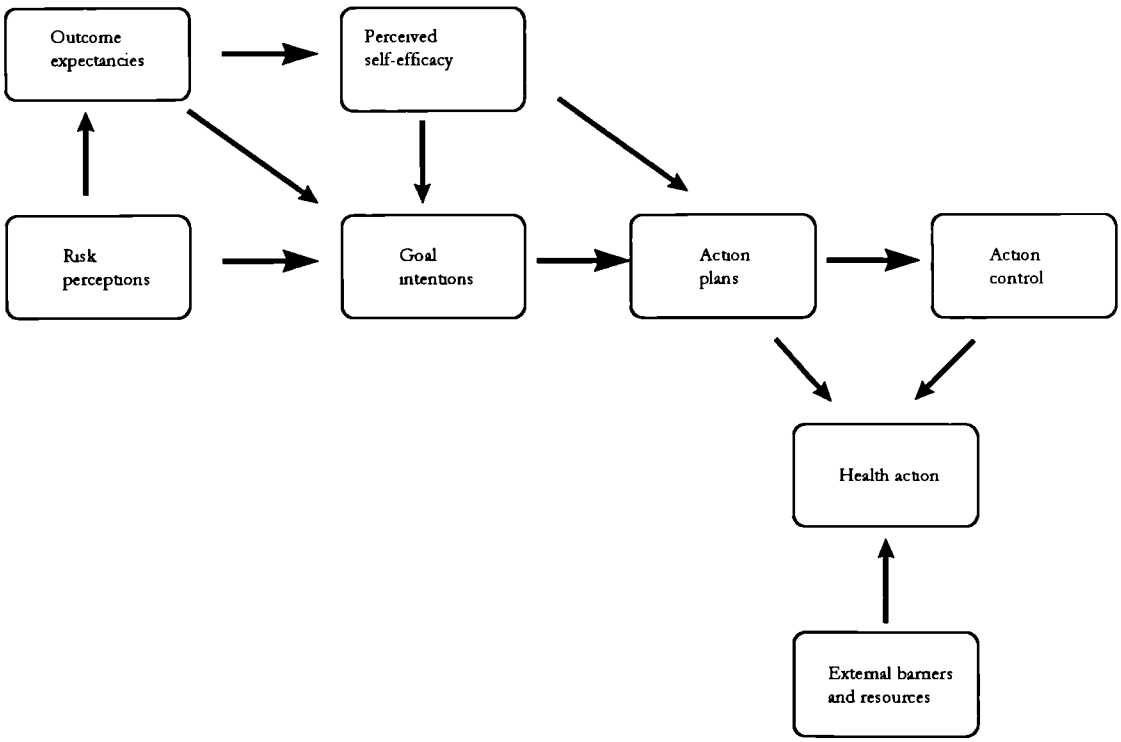


Figure 3.3 The Health Action Process approach (adapted from Schwarzer and Fuchs, 1996)

Weinstein (1988), suggests that some of the cognitive components of SCMs, such as beliefs about personal susceptibility, are also best described in stages.(e.g. is aware of a potential health risk, believes that others are susceptible, believes that they are personally susceptible). He goes on to suggest that interventions to promote behaviour are likely to be more effective if they are targeted at the particular cognitions which characterise the

particular stage that the individual has reached in their thinking about or implementation of the behaviour (Weinstein, 1988). There is considerable overlap between the Staged models described above. In all of these, the expectancy-value deliberations implicit within SCM occur as part of a motivation phase which must then be translated into action. In the HAP self-efficacy beliefs are the link between motivation and action. Self-efficacy (and hence the HAP) may be particularly relevant to behavioural changes which are perceived as difficult, such as giving up addictions such as cigarettes or alcohol or adopting dietary restrictions. However, it is more difficult to accept such a pivotal role for self-efficacy beliefs when simpler behaviours such as taking a daily dose of medication are considered.

Stage models seem to be limited when one attempts to use them to explain variations in intentional non-adherence to medication over the course of a chronic illness chronic illness. The key issue here is maintenance of the behaviour. Although, the processes of initiation and *maintenance* of behaviour are recognised in the HAP and TM, there is an implicit assumption that the main cognitive barrier to maintenance is low self-efficacy. If the patient is motivated to take it and believes realistically that they can carry out the behaviour, then they will continue to do so.

Leventhal has suggested that once self-efficacy and outcome efficacy beliefs are in place, continued behaviour depends on continued motivation and one criticism of SCMs and the staged models derived from them is that they do not fully address the issue of how motivation to continue with the health-behaviour is maintained (Leventhal, 1993). In an attempt to explain the dynamic interaction between cognitions motivation and behaviour Leventhal and colleagues have developed a Self-Regulatory Theory as a framework for understanding illness behaviour. This is often referred to as Leventhal's Self-Regulatory Model (SRM). The next chapter will describe this model and how it can applied to explain variations in medication adherence among patients and within a single individual over time.

CHAPTER 4

Leventhal's self-regulatory model of illness: from social cognition to self-regulation

Leventhal's self-regulatory model (SRM) was derived from early work investigating the impact of fear-arousing communications on preventive health behaviour. Studies showed that although a threat message was often necessary to motivate people towards preventative health behaviours such as taking a tetanus vaccination or giving up smoking, the threat alone was often insufficient. In order to achieve behavioural change it was necessary to add an action plan to the threat message -e.g. by giving clear instructions for successful action and helping the individual to incorporate this into their daily routine. This cognitive -behavioural approach generated actions which lasted longer than any fear aroused by the threat which had faded within a day or two. Leventhal surmised that the combination of fear and action plan had changed the 'cognitive representation' of the threat. This stimulated interest in how people represented heath threats and the interaction between representations and behaviour which led to the development of the self-regulatory model (SRM).

4.1 The self-regulatory model: an overview

The fundamental premise of the SRM is a view of the patient as an active problem solver, whose health-related behaviour is an attempt to close the perceived gap between current health status and a future goal state. Threats to health and illness are regarded as a problem and the patient's behaviour is seen as an attempt to solve the problem. Patients respond to illness in a dynamic way based on their interpretation and evaluation of the illness. The choice of a particular coping response (e.g. to take or not to take medication) is influenced by whether it makes sense in the light of their own ideas about the illness and personal experience of symptoms. Responses to illness follow three broad stages:

1. The cognitive representation of the health threat by which the patient identifies the meaning of the health threat. This can be stimulated by internal (eg symptoms) and or external (eg information) cues.
2. The development and implementation of an action plan or coping procedure to deal with the threat.
3. The appraisal of the outcome of the action plan.

Key features of this model are that the three stages of processing occur in parallel at a cognitive and emotional level and that there is a dynamic interaction between the processes of representation', coping and appraisal. In Figure 4.1 it can be seen that the interaction proceeds in both directions.

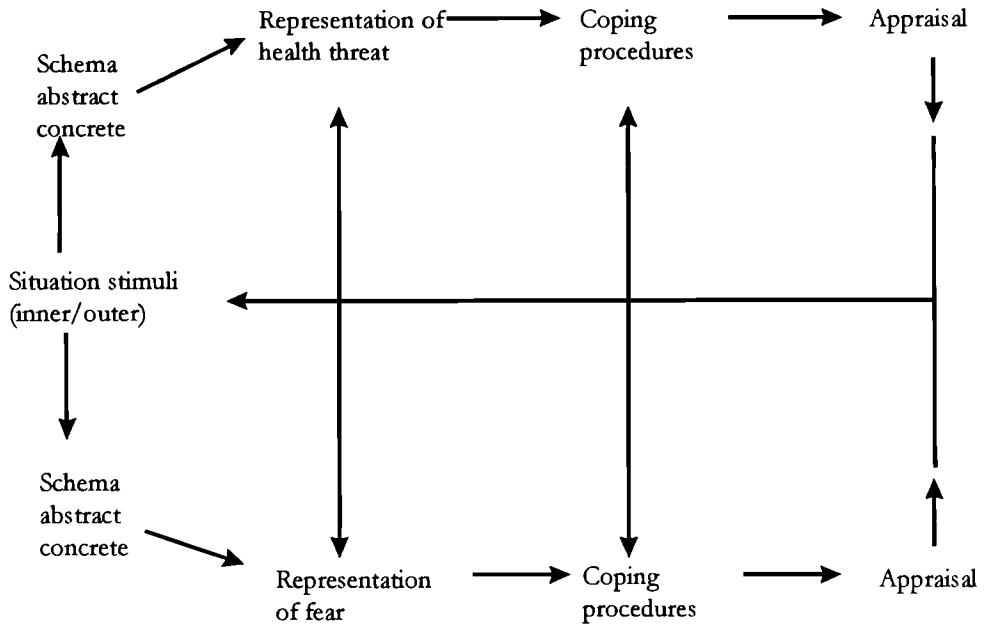


Figure 4.1 Parallel Processing Model for adaptation to health threats: internal and external stimuli make contact with and are processed elaborated upon by both conceptual (abstract) and concrete (perceptual) memory schemata to form representations (experience) of both health threats (danger) and emotion (fear). The features of these representations initiate and shape procedures for coping. The effects of coping upon the representations are appraised in relation to expectations about the effectiveness of the coping response and the nature of the representation (e.g. is the symptom a sign of a transient or a serious, chronic condition). Appraisals feed back and update the representation, changing, for example, the identify of the problem, its controllability, etc. and changing expectations respecting the effectiveness of the coping procedure. Not shown but also appraised is the individual's perception of his effectiveness in performing these actions, and his perceptions of the effectiveness of his support (expert and non-expert) system (from Leventhal, 1993).

For example, the patient's coping and appraisal may arise from a particular and individual representation of the health threat, but equally the perceived outcome of coping may feed back to influence the representation. In common with SCMs the SRM attempts to focus on the individual's cognitive representation of the health threat as the key factor determining

variations in behaviour. The SRM differs from SCMs and staged models in its emphasis on appraisal processes and the resultant feedback effect on cognition and behaviour. The interaction between cognition and behaviour is therefore seen as a dynamic process, rather than the result of a single or staged decision. The selection of a coping procedure (e.g. giving up smoking or taking medication) is determined by beliefs about the nature of the illness threat (e.g. "This pain is a headache which needs to be treated. Taking aspirin is easy and effective. My partner thinks I should take a tablet now. I will get a glass of water and do so"). This is then followed by an appraisal stage in which the patient evaluates the efficacy of their coping strategy (e.g. the pain is still there three hours after taking the aspirin). If the patient appraises a particular coping strategy as being ineffective then this might result in the selection of an alternative coping strategy (e.g. "I will try a stronger pain killer") or even a change in the representation of the illness (e.g. "Aspirin hasn't worked, this might be something more serious than a headache").

The fact that cognitive and emotional processing occur in parallel may be used to explain responses to illness threats which are apparently irrational. For example, a patient may believe that the lump in her breast is likely to be a tumour but delays seeking help because she fears the diagnosis (Phelan et al. 1992). Her behavioural response (to delay seeking help) can be seen as a way of coping with the emotion (fear/distress) generated by the cognitive representation, which may be reinforced by her appraisal that the lump doesn't get bigger and 'the less she thinks about it the better she feels'. The SRM also emphasises the importance of concrete symptom experience in formulating representations and guiding appraisal of the efficacy of the coping procedure. Perceptual experiences are seen to be generally more persuasive than abstract ideas.

Personal representations of the illness drive coping and appraisal and the question of how sick individuals conceptualise their illness is central to the SRM. An important difference between the SRM and SCMs detailed in the previous section is in how relevant beliefs are conceptualised. In both approaches, beliefs are of paramount importance in guiding behaviour. However, in SCMs, beliefs are characterised as outcome expectancies and the values placed on or are limited to beliefs about the behaviour. Leventhal asserts that the models are deficient in that they 'attempt to explain the process underlying choices in the absence of constituents of the choice process' (Leventhal E, A and Crouch, in press).

Thus, Leventhal and colleagues have devoted much attention to the cognitive representations of illness and have identified two important aspects: content (an

individual's ideas about the illness) and structure (how these ideas are cognitively organised). They suggest that people form 'common-sense' models of disease and illness organised around five components: identity, cause, consequences, time-line and cure. Identity consists of concrete symptoms and signs and an abstract label associated with them. Cause relates to perceived ideas about how one gets the disease. Time-line relates to perceptions about the likely course of the condition and how long it will last. Consequences are the expected outcomes in physical, psychological and social terms and cure deals with the person's beliefs about the potential for cure and control. Leventhal argues that the specific content of each component is influenced by the cultural context (Farmer and Good, 1991; Farmer, 1988; Blumhagen, 1980; Landrine and Klonoff, 1992) and by other factors such as past experience and the views of *significant others* (Leventhal et al. 1992a) and, although the particular content of the individual components of illness representations often change (Meyer et al. 1985), the components are stable over time (Bishop, 1991).

Before going on to outline the empirical support for the SRM, I will discuss the content and structure of illness representations in more detail.

4.2 The structure of illness representations: empirical studies

Significant empirical and theoretical contributions to the study of illness cognitions have arisen from three disciplines: medical anthropology, medical sociology and health psychology. For each discipline, the fundamental concern has been to understand the meaning of illness from the patient's perspective(Croyle and Barger, 1993). Studies in medical sociology and anthropology have focused on the content of illness representations, eliciting detailed descriptions of lay ideas about illness (Radley, 1993) whereas health psychologists have been concerned with how representations are cognitively organised. Psychological approaches are characterised by a strong theoretical basis (Leventhal, 1985; Meyer et al. 1985; Leventhal et al. 1980) and the application of statistical methods and experimental research designs.

A more detailed exploration of how people think about illness may augment SCMs as these tend to deal with the interactions between beliefs and their influence on behaviour, and pay little attention to the nature of the beliefs. For example, the HBM illustrates the importance of beliefs about personal susceptibility, but does not specify how an individual

judges his/her degree of susceptibility. An exception to this is the locus of control construct which suggests that beliefs about control are structured around three dimensions: internal, chance/fate and *powerful others*. Knowledge of cognitive structures can be used to identify the pivotal constructs which should be empirically assessed in studies linking cognition and behaviour.

One of the first investigations of the structure of illness cognition was conducted in the USA by Jenkins and colleagues (Jenkins, 1966; Jenkins and Zyzanski, 1968). Factor analysis was used to identify the underlying structure of responses to a 16-item semantic differential scale assessing views about the seriousness, susceptibility and preventability of several diseases including cancer, poliomyelitis, tuberculosis and mental illness. Three core factors were identified and labelled as *personal involvement*, *human mastery* and *social desirability*. In developing an empirical approach to the question of illness cognition, this work made a useful contribution to the field. The rationale for the study stemmed from a public health perspective, rooted in the notion that a better understanding of how well individuals conceptualise diseases could inform the development of preventative strategies. However, the scope of the findings was limited by the fact that the items used in the semantic differential scale were chosen by the researchers and therefore may not have represented the way in which their subjects would normally conceptualise these illnesses.

There is limited empirical support for the theory that illness representations are cognitively structured around the five components suggested by Leventhal (Schober and Lacroix, 1991). Early studies in which patients from a range of chronic illness groups were asked to talk openly about their illness. Multidimensional scaling of coded responses showed that they tended to congregate around four dimensions labelled as *identity, cause, timeline and consequences* (Leventhal and Nerenz, 1985). The list of attributes was extended to include the *cure* component following a study examining beliefs about common mild illness (Lau and Hartman, 1983). In this study, Lau and Hartman found that when 250 American college students were asked to recall a recent episode of minor illness and to describe why they got ill and got better, most subjects had a ready explanation for why they had recovered. A factor analysis of coded attributions for getting better produced a three factor solution labelled as *passive* (e.g. it just went away) *external* (e.g. doctor, treatment) and *internal* (e.g. change of habit, sleep, rest) control beliefs. Leventhal has argued that these beliefs are also components of common-sense representations of severe or chronic illness but may be more focused on *controllability* rather than *cure* of a disease.

A separate research group led by Bishop also found information about diseases to be structured around the five components suggested by Leventhal (Bishop et al. 1987). Undergraduate students were shown sets of symptoms which had supposedly been experienced by 'a friend' and were asked to describe any other details with might be associated with their friend's situation. In this experiment the two aspects of the identity component, label and symptoms, were coded separately and, allowing for this, 91% of the open ended responses could be categorised in a way which was consistent with the 5-components model: label (25%), symptoms, in addition to those specified by the investigators (14%), cause (29%), control/cure (13%), consequences (8%) and timeline (3%).

A further exploration of the structure of representations of common illnesses provides convergent data supporting the five-component model. Lau and colleagues asked over 450 college students to write about a recent illness in their own words. The responses were independently coded into 89 items. The ease with which these could then be grouped into the 5 illness components was taken by the authors as qualitative evidence of the suitability of the 5-component structure. Similar groupings were chosen by 20 nad've participants who were asked to group 65 responses into categories. The mean number of groups was 6 (range 4-8) and these could be readily assigned to the five components of identity , cause, timeline, consequences and control/cure. Discrepancies were attributed to the tendency of participants to assign label and symptom constituents of the identity component into separate categories and to differentiate several different types of consequences (e.g. social, emotional, behavioural). Illness accounts elicited over a three separate time-points produced similar groupings suggesting that the components, though not necessarily the content, of illness representations are stable. The authors also presented additional evidence to corroborate their view in the form of a path analysis using the tendency to visit the doctor over a three year period. The five components of illness representation were identified as separate latent factors, which together with a measure of self-rated health explained 29% of the variance in tendency to visit the doctor.

Further anecdotal support for the stable structure of illness representations has been obtained from diaries and articles written during the Enlightenment Period (circa 1600-1762). Content analysis of sections relating to illness showed that the material was structured around the five components of illness representation identified by Leventhal (Schober and Lacroix, 1991).

The structure of illness cognition has also been studied by Turk, Rudy and Salovey (1986) in a sample of diabetic patients, healthy nurses and college students who completed questionnaires about flu, diabetes and cancer. Factor analysis of the responses identified a four-dimensional structure (*seriousness, personal responsibility, controllability and changeability*) which was confirmed on a second sample drawn from the same group. Although, at first sight, this interpretation appears to have little in common with the five components identified by Leventhal, the apparent discrepancy may be a feature of the type of analysis used. Turk and colleagues used factor analysis (FA) to identify the core dimensions of cognitions about three very different illnesses, whereas the Leventhal and Bishop groups used multidimensional scaling (MDS) techniques. Lau and colleagues (1989) suggest that different aspects of cognitive structure are identified by these techniques. MDS is used to identify areas of consistency within qualitative data, whereas FA identifies the core dimensions explaining variance within the data. Thus, the four factors identified by Turk's group are analogous to cognitive categories used by participants to differentiate between particular diseases. This solution is not incompatible with Leventhal's 5-component structure and it has been suggested that these findings represent complimentary aspects of the same phenomenon (Croyle and Barger, 1993; Bishop, 1991). For example, views about seriousness, personal responsibility, *changeability*, and controllability might arise from prototypic beliefs structured around *identity*, *cause*, *consequences*, *timeline* and *cure*. In particular, the *changeability* of a disease is akin to its *timeline* and notions of personal responsibility may arise from *causal* beliefs. Moreover, *seriousness* and *controllability* are related to the *consequences* and *control/cure* components. It is therefore plausible that people's ideas about different diseases are structured around the four factors identified by the Turk group but that it is the perceived features of the disease in terms of *identity*, *cause, timeline, consequences* and potential for *cure/control* which determines how a particular disease is categorised. Bishop (1991) has suggested that while the components approach deals with the specific content, and identifies the 'basic building blocks' of disease representation, the dimensional (FA) approach identifies the cognitive dimensions by which people evaluate the content. Further work is needed to establish the validity of the Turk groupings in other samples and to explore how these relate to the five components suggested by Leventhal.

4.3 The interpretation of health threats: disease schema, prototypes, and stereotypes

The research described in the above section provides limited evidence that people structure their ideas about illness in common ways and that it is possible to identify core dimensions by which illness threats are evaluated. A further topic of theoretical speculation and empirical investigation relates to the mechanism by which illness representations are formed and acted upon. Leventhal emphasises the importance of past experience in the interpretation of disease threats. The past experience of the subject and those of *significant others* is stored as a memory schema based around the concrete experience of symptoms. These schemata play a prominent role in the interpretation of a current health threat. For example, the experience of symptoms or being told that one has a disease results in a cognitive process in which current concrete experience or abstract information is evaluated in relation to an appropriate memory schema.

Pennebaker (1982) has shown that illness schemata and symptom perceptions are closely linked. Moreover, analogue studies of symptom perception in university students has shown that the influence is bi-directional. Not only does the experience of symptoms influence the content of illness schemata but arousal of a memory-based schema initiates a search for confirmatory symptoms. The influence of illness representations on symptom perception is further corroborated by recent studies in which people presented with a false diagnosis tend to report symptoms which confirm their representation (Bishop, 1991). These findings are relevant to the concept of illness as distinct from disease. It is well recognised that there is often considerable discrepancy between, the subjective impact of a disease (e.g. symptom reports) and the underlying pathology. This has led to a distinction between disease and illness with illness defined as the subjective experience of a disease (Mechanic, 1962). Thus illness schemata can be conceptualised as the link between medical pathology and disability (Lacroix, 1991).

Bishop argues that people hold quite elaborate representations of common diseases which he terms *disease prototypes*. He argues that when faced with a health threat (e.g. experience of chest pain or being told that they have had a heart attack), people refer to disease prototypes to confirm the diagnosis and decide what to do. (e.g. "This can't be a heart attack, I walked to the Emergency department. People with heart attacks are rushed to hospital in an ambulance!"). This idea is not incompatible with Leventhal's emphasis on past experience as this is likely to be an important determinant of the disease prototype.

There is a degree of empirical support for the existence of disease prototypes and their role in the interpretation of health threats. Studies in which adult volunteers were asked to rate the perceived association between lists of symptoms and common diseases such as sore throat, stroke and hay fever suggested that certain common diseases are associated with particular symptom clusters. Furthermore, symptoms could be grouped according to how well they fitted a particular disease prototype (Bishop and Converse, 1986). Moreover, the perceived degree of *prototypicality* of a particular symptom set influenced the accuracy and speed of recall, which was regarded as evidence that highly prototypic symptoms were present in existing cognitive structures (Bishop et al. 1987). Other studies indicate that prototypic beliefs about particular diseases and symptoms may be classified according to their perceived *causes* (e.g. viral, non-viral) and *consequences* (contagious, life-threatening) as well as according to the symptom clusters (*identity*) associated with them (Bishop, 1991).

Croyle suggests that perceptions of a particular disease are affected by illness stereotypes or beliefs about 'the type of people who contract it'. Laboratory studies using hypertension as an example showed that the degree to which the disease was associated with positive or negative personal attributes varied among student volunteers. The effect of disease stereotype on perceptions of severity and symptom reporting was investigated in a second study by manipulating a diagnosis of hypertension. Participants who were given false information that their blood pressure was raised, together with data supporting a positive stereotype of hypertension (e.g. research had shown that people with hypertension were more likely to be academically successful and hold down professional jobs), rated the condition as less severe and reported more symptoms than those who were supplied with a diagnosis and negative stereotype (e.g. research had shown that people with hypertension were more likely to fail academically , hold "dead-end" jobs and panic in a crisis). (Croyle and Barger, 1993; Croyle and Williams, 1991). The idea that disease stereotypes might influence the interpretation of symptoms has clear implications for delay in seeking help, particularly in the case of acute myocardial infarction. Patients who perceive themselves to be atypical in relation to the stereotype may delay seeking help (e.g. "This can't be a heart attack, I'm not an overweight stressed executive, it's probably indigestion"). Croyle also provides preliminary evidence that perceptions of the degree of severity of a particular disease are strongly influenced by perceptions of its prevalence; being told that a disease is common seems to reduce its perceived severity (Croyle and Ditto, 1990).

4.4 Empirical support for a self-regulatory model

In the above section I have described some of the empirical support for the notion that people form common-sense representations of disease the content of which may be structured around various themes. But what is the evidence that cognitive and emotional aspects of illness representation drive the selection of coping procedures and provide a framework for appraisal in accordance with the SRM? Unfortunately, the SRM does not readily lend itself to empirical evaluation. The strength of the SRM is that it encompasses emotional and cognitive antecedents of health-related behaviour in a flexible feedback model which also allows for the influence of cultural and social-environmental factors. However, this inherent complexity makes it very difficult to operationalise the model as a whole.

A further impairment to the empirical testing of the model is that, although the relevant components of the cognitive representation of illness are clearly specified, there was until recently no standard method for operationalising the representations construct. Consequently, there is little uniformity across studies published before 1995. This problem has recently been addressed by the development of the Illness Perception Questionnaire (IPQ), a validated method for the quantitative assessment of the 5 components of illness representations (Weinman et al. 1996)

In the absence of a full validation of the SRM as a whole one is left to judge the merits of the self-regulatory approach on the basis of studies which have empirically evaluated certain key tenets of the model. Some of these studies provide indirect support for a self-regulatory approach whereas others have specifically used the model to conceptualise their research question.

4.4.1 Illness representations have concrete (symptoms) and abstract (label) features, and influence behaviour (coping) in response to health threats

The importance of symptom perception in influencing illness representations and behaviour was reinforced by work with diabetic individuals who used perceived symptoms to indicate their blood glucose levels and to guide self-treatment. However, patients' beliefs about their symptoms, and blood glucose estimations based on them, were often erroneous and resulted in poor diabetic control (Gonder-Frederick and Cox, 1991).

Further evidence of the importance of illness representations was obtained by Meyer and colleagues who noted a clear relationship between representations and behaviour in their study of hypertensive patients (Meyer et al. 1985). Timeline representations at baseline influenced subsequent drop-out from the treatment programme. Patients who held an acute representation of hypertension were more likely to drop out of treatment than those who believed it to be a chronic condition. This study also showed that patients' representations of the illness often conflicted with medical rationale and provided an insight into the effects of a mismatch between the patients' representations and those of their doctors. In a group of 50 patients who had continued in treatment 80% agreed with the statement that " people cannot tell when their blood pressure is up". However, 92% believed that they could tell when their own blood pressure was up by monitoring symptoms such as tiredness , headache and stress. Furthermore, the patients tended to behave in accordance with their own representations rather than those of their doctors in that representations influenced treatment adherence. Patients who believed that their anti-hypertensive medication improved symptoms were significantly more likely to take it. A striking example of this was provided by 5 out of 17 patients who believed that their medication affected symptoms. These patients took their anti-hypertensive medication only when they judged their blood pressure to be up. The patients had understood and accepted the abstract medical view of hypertension as an asymptomatic condition but their concrete experience of symptoms caused them to hold contrasting beliefs and to behave according to these.

4.4.2 Illness representations influence care-seeking

Studies conducted by the Leventhal group have shown that illness representations, in particularly the identity component assessed as symptom reports, influence care-seeking (Booth et al. 1986; Cameron et al. 1993). A further study showed that one of the factors influencing delay in seeking medical care showed that that certain features of the cognitive representation of illness were associated with delay in care-seeking. For example, patients who acknowledged that they were ill but who imagined that the consequences of seeking help would be severe (e.g. "picture myself lying on the operating table") were more likely to delay care-seeking (Safer et al. 1979).

4.4.3 Representations of illness influence disease outcome

Cognitive representations of illness were found to be the strongest predictors of psychological adjustment in a postal survey of 233 patients with Chronic Fatigue Syndrome (CFS). Using multiple linear regression analyses Moss-Morris and colleagues showed that patients' responses to the IPQ, which assesses the five components of illness representation, explained a significant proportion of the variance in dysfunction (37%), psychological adjustment (30%) and vitality (42%). It is worthy of note that illness representations had a much more powerful effect on outcome than did the coping strategies used by patients.

Further support for the SRM comes from a prospective study of 143 patients with first myocardial infarction in which patients beliefs, elicited shortly after their heart attack, were predictive of outcome (Petrie et al. 1996). Return to work within 6 months was significantly predicted by perceptions that the condition would be of short duration and have less severe consequences. Initial beliefs that the heart attack would have severe consequences predicted a higher degree of impairment of social interaction, recreational activities and participation in housework at three and six month follow up. Relations between representations and outcome were independent of clinical measures of MI severity and number of days spent in hospital.

There is further evidence that, in chronic illness, patients' representations may be mediators of distress and disability. Fisher and Johnston have investigated the role of cognition and emotion as mediators between pain and disability among patients with chronic pain. In one study perceived control (PC) over pain problems was successfully manipulated using focused attention and selective recall. Cognitive manipulation was associated with changes in control beliefs and disability in the predicted direction. However, changes in disability could not be explained by changes in control beliefs as these parameters were not significantly correlated (Fisher and Johnston, 1996a). In a further study, mood appeared to mediate between control beliefs and disability (Fisher and Johnston, 1996b). Although not based on the SRM, this study supports the general principle that emotional and cognitive representation are related and may influence outcome.

4.4.4 Representations influence coping procedures

In their study of patients with CFS, Moss Morris and colleagues noted that cognitive representations and coping were related in a conceptually logical fashion which was consistent with earlier studies supporting a link between representations and coping and suggested by the SRM (Leventhal et al. 1992a). However, relatively few other studies have systematically evaluated interactions between representations and coping. One of the impediments to this type of study is the paucity of reliable, valid measures of coping which encompass the wide range of strategies used by patients. Most available measures conceptualise coping in terms of broad dimensions such as problem-focused, emotion-focused or avoidance-based strategies (Carver et al. 1989). The findings of Moss-Morris and colleagues reinforce recent calls for a more complete assessment of the coping process which takes account of the cognitions which determine the selection of the coping strategy.

4.4.5 Representations influence adherence to treatment programmes

Despite a cogently argued rationale for the study of illness cognitions as determinants of treatment adherence (Leventhal et al. 1992; Leventhal and Cameron, 1987; Leventhal et al. 1984), very few studies have utilised this approach. Exceptions are the studies detailed above in which illness representations were related to medication adherence in hypertension (Meyer et al 1985), and regimen adherence in diabetes (Gonder-Frederick and Cox, 1991). In a recent prospective study, attendance at rehabilitation classes after discharge from hospital was predicted by illness beliefs (identity, consequences, control/cure) elicited during hospital convalescence following a first myocardial infarction (Petrie et al. 1996).

4.5 Applying the SRM to medication adherence

The SRM provides a useful conceptual framework for understanding intentional non-adherence. If taking medication is seen as a form of coping procedure, then the model posits that the decision to follow treatment recommendations will be influenced by the patients' representations of the illness and their subsequent appraisal of the treatment effects. The dynamic interaction between representations, coping (e.g. adherence to the advised treatment) and appraisal (was adherence to treatment beneficial?) is guided by the person's need to maintain *coherence* between these processes. In essence the patient self-regulates their response to the illness threat in an attempt to achieve "common sense"

coherence. Non-adherent behaviour can be seen as an attempt to maintain coherence between representation and coping in a way which makes "common sense" and which is heavily influenced by the experience of concrete signs and symptoms. ("Why take this medicine when I don't feel ill?" or "When I take this medicine I feel drowsy and tired when I stop taking it I feel fine. Maybe I'm not that ill and I'll just see how I get along without the medicine"). Adherence is more likely if there is a high degree of coherence between the abstract (ideas) and concrete (symptoms) aspects of the illness representation and if health care providers advice seems "common sense" in the light of the patients' own experiences and representations.

4.5.1 Treatment beliefs and the self-regulatory model

The SRM emphasises the central role of illness representations in guiding adherence decisions. However, a possible limitation of this approach is that the self-regulatory patient will not just have their own ideas about the illness but also about the *treatment* being offered. Thus from Leventhal's view of the patient as an "active problem solver" it follows that, in deciding whether to adhere to a treatment schedule, the patient has to think not only about whether the illness warrants treatment but also whether the treatment is appropriate for the illness. Thus a better understanding of the interplay between representations of illness and treatment and treatment adherence might contribute to the further development of Leventhal's' SRM.

Bishop (1986, 1987) and Croyle (1991) have shown that people often hold prototypic beliefs about certain diseases which have an important role in illness cognition. It may also be true that the prominent place of medicines in health care has resulted in the formation of prototypic beliefs about medicines. People may have preconceptions or schema about *medicines in general* which might influence attitudes towards prescribed medication and personal beliefs about the most appropriate treatment for a particular disease.

The following chapter will focus on the issue of patients' beliefs about medication.

CHAPTER 5
A resume of research into beliefs about medicines

The published research dealing with people's beliefs about medicines falls into several broad categories. The first is essentially exploratory research into patients' knowledge of and views about medication which does not appear to have been guided by particular psychological theories but has produced insights into lay beliefs about medicines. A second type studies patients' beliefs about taking medication within the context of social cognition models. A third category comprises qualitative research eliciting patients' perspectives of illness which have identified lay representations of medication or which set out to discover the content of people's representations of medicines. Finally, a few studies have quantitatively assessed medication beliefs and systematically investigated relationships between medication beliefs and other variables.

Taken collectively this work has shown that people form beliefs about their medication and the meaning of medication-taking and suggests that such beliefs may influence self regulation. Additionally, although these studies have involved a range of patients from several diagnostic groups and socio-cultural backgrounds, they seem to have uncovered common themes which will now be discussed in more detail.

5.1 Views about the general nature of medicines (healing and harm - the dual nature of medicines)

An interesting insight into patients' beliefs about medicines was provided by Fallsberg (1991), who used a phenomenographic approach to analyse conceptions of medicines elicited during interviews conducted with 90 chronically ill Swedish patients who had been prescribed regular medication for a range of conditions (asthma, hypertension and chronic pain). She identified several broad "conceptions" - or value judgements -about medicines in general. These included a singularly positive view of medicines derived from the beneficial effects of medicines and the idea that medicines work in unison with the body to promote health. Other patients expressed an essentially negative view which stressed the harmful effects of medication and in which medicines were seen either as a form of poison which should be avoided if possible, or as a "necessary evil". A third category emphasised the

dual nature of medicines as carrying the potential for harm as well as benefit. For this group, the harmful effects of medication are intrinsic so that one cannot have the positive effects without the negative. Efficacy and toxicity somehow go hand in hand and that more effective medicines implicitly, have more side-effects (Lorish et al. 1990). Similar categories were also identified by Britten in a more recent study of attitudes to medication in a sample of general practice patients in the UK (Britten, 1994).

These finding are analogous to those obtained in an earlier study conducted in the USA, which used the Theory of Reasoned Action (TRA) to guide the development of questions to elicit rheumatoid arthritis patients' perspectives on missed dosages of their medicines (Lorish et al. 1990). Patients' definitions of a "powerful" medicine were explored and questionnaire responses revealed that "powerful" was defined solely by the degree of *symptom control* (35%), solely by *potential to cause harmful side-effects* (33%) or by a *combination* of both (32%).

Leventhal's group have shown that representations of the dual nature of medicines can influence response to symptoms. In one study, a number of women with breast cancer interpreted the experience of side-effects of chemotherapy as a sign that the drugs were working. For these women, the absence of side-effects was a distressing indication that "chemotherapy was not having enough *beneficial* impact upon the body" (Leventhal et al. 1986).

5.2 Beliefs about efficacy

It seems reasonable to hypothesise that a belief that prescribed medication is necessary and potentially effective may be a key determinant of intention to adhere to treatment. It is also not surprising that some people use the perceived effects of their treatment to judge its efficacy. These judgements are usually based on symptom relief or the perceived effect of drugs in bringing back or retaining normal functioning (Conrad, 1985; Arluke, 1980). It is interesting that, although none of these studies have utilised Leventhal's SRM, they seem to support the importance of concrete symptom experience in guiding self-regulation (Leventhal et al. 1986; Leventhal et al. 1992).

Another representation related to efficacy has been identified in at least two studies. This is the view that if medication is taken continuously it will become less effective. The notion of becoming "immune" to the beneficial effects of the medication has been noted among

rheumatology patients in the UK (Donovan and Blake, 1992) and in the USA (Lorish et al. 1990), who were concerned that regular use of the medication would reduce its analgesic effects.

5.3 Negative views about medication

Several studies have identified beliefs which were associated with a negative view of medication.

5.3.1 Addiction and dependence

A recurring theme associated with negative attitudes to medicine is the notion that chronic use of medication carries the risk of dependence or addiction. It is difficult to pinpoint the precise meaning of these terms and they are often used interchangeably. In a medical context, "addiction" is usually defined as a state of psychological and physical dependence. Relatively few medicines are thought to have this property, which is generally limited to psycho-active/mood-altering drugs. However, fear of becoming addicted or "too dependent" on medication has been cited as a key reason for intentional non-adherence by patients receiving medication for a range of diseases including hypertension, epilepsy and asthma (Fallsberg, 1991). Conrad, in his study of people with epilepsy, found that the notion of addiction or dependence was linked to the perception of having to take medication as a "threat to self reliance" and that some patients saw their medicines as symbolic of the dependence created by having epilepsy. In this context self-regulation of medication could be interpreted as a means of "gaining control" (Conrad, 1985).

5.3.2 Long-term dangers

In this representation the *continuous* use of medication is associated with obscure long-term effects. For example, Morgan and Watkins (1988) found that several patients decided to stop taking their anti-hypertensive medication for periods of time lasting up to a few months, in order to give the body a break from medication. People's concerns seem to arise from perceptions of danger associated with medicines in general rather than from the personal experience of adverse effects. This is illustrated by a study conducted in the USA in which respondents who had never taken diazepam (a benzodiazepine tranquilliser) attributed more dangers to its use than those who had taken the drug in the past (Mansbridge and Fisher, 1984).

5.3.3 Chemical vs natural

This representation relates to the perceived means of production of medicines. Although the term "natural" was not clearly defined, labelling of a treatment in this context was associated with a value judgement in which "natural" remedies were seen as safer than "unnatural" medicines and that the dangerous aspects of medication were linked to their chemical/unnatural origins (Conrad, 1985). People with this view may prefer to avoid medication altogether. For example, in a study of women who had been prescribed benzodiazepine tranquillisers for menopausal symptoms, several explained that they chose not to take them because of concerns about the potential harm which could arise from the use of "unnatural" medicines. The symptoms of the menopause, although uncomfortable, were at least "natural" and were therefore perceived as a more favourable alternative to medication (Gabe and Thorogood, 1986). Similarly, parents who had chosen not to have their children vaccinated contrasted the "unnatural" process of immunisation with the "natural" immunity possessed by the body, or the "natural" phenomena of pertussis (whooping cough) (New and Senior, 1991).

5.3.4 Medicine as poison

The Ancient Greeks did not make a linguistic distinction between medicine and poison but used the same word "pharmakon" to describe both types of substance (Bonuzzi, 1987). This seems to be reflected in a contemporary representation of medicines found among Fallsberg's (1991) sample of Swedish patients

5.4 Doctors' overuse of medicines

In an early UK study of general practice patients' views of medicines and prescribing, over a third of the sample thought that doctors prescribed too many medicines, but the prevalence of this view varied according to class of medicines, between antibiotics (23%), antidepressants (30%) and tranquillisers (over 50%). People also had clear views about the purpose of certain medicines and this seemed to influence their expectations for treatment. The fact that about a third of the sample thought that medicines were overused by doctors implies an undercurrent of suspicion about medication. In a large survey of public attitudes to benzodiazepines in the USA (Clinthorne, 1986) and in a recent interview-based study conducted in the UK (Britten, 1994a), patients have also expressed the view that doctors prescribe too readily and use too many medicines. However, several studies have reported that patients use the number and dosage of medications prescribed

for them as an indication of severity of their illness and fluctuations in dosage as markers for improvement or deterioration (Donovan and Blake, 1992; Morgan and Watkins, 1988; Leventhal et al. 1991a).

5.5 Quantitative studies linking medication beliefs, illness beliefs and health behaviour

Most of the representations of medication described above have been identified from interview-based qualitative studies. Although this method provides detailed information this type of data is time-consuming and expensive to collect and analyse and this obviously limits the sample size. It is therefore difficult to obtain a clear insight into the prevalence of certain beliefs. Furthermore, a systematic investigation of the relationship between specific beliefs and behaviours is beyond the scope of qualitative methods. Surprisingly few studies have attempted to quantify people's beliefs about medicine and to systematically investigate the relationship between medication beliefs and other variables.

One exception is a study of 62 German patients with asthma in which those who emphasised the threatening aspects of corticosteroid medication were less adherent to treatment (Woller et al. 1993). The sub-scale which measured the "threatening aspect" of steroids contained four items. These were responses to the statements "When I think of cortisone tablets: (1) I'm afraid, (2) I feel threatened, (3) I feel despair, (4) I think I will get addicted". This latter statement provides preliminary, evidence that the representation of cortisone as potentially addictive contributed to avoidance of this medicine.

A further questionnaire based study conducted by Eagleton and colleagues (1993) found that attitudes to medication were not associated with medication adherence assessed by tablet count in fifty UK patients interviewed at home within two weeks of being discharged from hospital. Although the sample was too small to allow firm generalisation, this study produced an interesting insight into medication beliefs. Over a third of the sample believed a visit to the doctor should result in the prescription of a medicine and over 40% thought that "*Medicines always make you feel better*". This highlights the point that, although most studies have identified beliefs about medication which are predominantly negative, positive views about medication may also be prevalent.

In another study, Echabe and colleagues (1992) investigated the impact of representations of health, illness and medicines on coping strategies and health promoting behaviour in 902

subjects from the Basque region. Representations of medicines were assessed using an 11 item questionnaire derived from semi-structured interviews and focus groups. Cluster analysis was used to assign respondents into groups based on their representations of health, illness, medicines and locus of control over health. Three distinct clusters were identified. The first accounted for 70% of the sample and comprised people with an "against medicine" representation. These people conceptualised health as a balance between mind and body, attributed illness to stress, pollution, lack of exercise and poverty, had an internal locus of control and held a predominantly negative view of medication. The second cluster was essentially "pro-medicine" and accounted for 12% of the sample. Here health was perceived as synonymous with being able to work and enjoy life. Control over illness focused on diet and exercise but also externally, with physicians and medicines being the factors contributing to recovery. Medicines were viewed positively. The third cluster (18%), was a "half-way" position between the other two. This study is one of the few to shed light on how people's beliefs about medication relate to other cognitions. Additionally, cognitions were linked to coping styles in that people with an "against medicine" representation tended to delay going for medical check-ups whereas those with a "pro-medicines " or "halfway" representation were more likely to attend for check-ups on time. The key finding here is that that views about health and illness and orientation towards medication appear to cluster together in a logical way. It is interesting that cluster analysis corroborates earlier qualitative evidence that attitudes to medication broadly fall into three groups. However, this type of distribution of views (some positive, some negative and some in between) could probably be identified for most issues! We are still left with the question of which specific beliefs underlie these "positive", "negative" and "in-between" attitudes to medicines.

5.6 Summary of literature review and implications for the present study

The effective management of most chronic illness hinges on patient-self care, particularly the appropriate use of medication. Many patients fail to do this and non-adherence to medication presents a significant challenge to research and practice within the health care domain.

Early research into medication adherence attempted to identify the features of a disease or treatment which acted as barriers to adherence. It searched for demographic factors and personality traits which identified "the noncompliant patient". The limitations of this

research are highlighted by findings that adherence rates often vary between treatments and over time within the same individuals. Most patients are non-adherent some of the time.

A more rewarding avenue of research focused on the identification and removal of barriers to adherence to individual treatment modalities which suggests that improving communication with clear, easily remembered instructions and tailoring the regimen to fit in with the patient's lifestyle enhances adherence in some situations. An interesting aspect of this work was the inclusion of patients' satisfaction with practitioner- patient interactions as a possible determinant of medication adherence. This acknowledges the role of motivation and sees that nonadherence may not just be the unintentional consequence of incompetence or lack of knowledge on the part of the patient. The recognition that what a patient thinks influences what they do stimulated more psychologically based research into medication adherence.

Social cognition models (SCMs) such as the Health Belief Model and the Theory Of Reasoned Action have been used to explain the interaction between peoples' beliefs and their behaviour in relation to health and illness. Although several studies have demonstrated the utility of these models in predicting adherence to medication they have generally proved to be more useful in predicting preventative behaviours than response to illness.

Leventhal and colleagues in the self-regulatory model (SRM) provide an additional theoretical framework for understanding psychological and behavioural responses to illness A key feature of the framework is that patients respond to illness in a dynamic way based on their interpretation and evaluation of the illness and the perceived outcome of the coping procedures which they adopt. Illness representations - an individual's beliefs about the identity, cause, consequences, time-line and potential for control or cure of their illness -drive the selection and appraisal of the coping procedure. Thus, if adherence is conceptualised as a coping procedure, the SRM suggests that a patient's own ideas about their illness will influence adherence behaviour and there is evidence to support this

However, relatively few studies have considered patients' beliefs about treatment. Research using the SRM focuses on illness representation and studies using social cognition models have tended to conceptualise beliefs about treatment as patients' perceptions of the relative benefits of adherence or barriers to taking medication without systematically

examining their underlying beliefs about medication. Greater emphasis on patients' beliefs about treatment may increase the explanatory power of SCMs and the SRM as treatment beliefs may be influential in shaping adjustment and behaviours such as adherence. Several qualitative studies have identified lay beliefs about medicines which conflict with the medical view and may influence treatment adherence. The representations of medicines, identified in these studies, appear to be common across several illness and cultural groups. However, a systematic comparison of findings is hampered by the fact that the few studies which have quantitatively assessed medication beliefs have used different questionnaires or have investigated medication beliefs in the broader context of views about the practice of medicine. Furthermore, some studies have assessed peoples' ideas about medicines in general whereas others have focused on specific medication prescribed for a particular illness.

The research described above provides insights into the content of peoples' beliefs about medicines together with a few hints as to how representations might influence attitudes and adherence to treatment. However a number of key questions remain unanswered. Although it identifies particular beliefs this research tells us little about the prevalence of these beliefs. We do not know the proportion of people who hold them or how strongly they are held. Furthermore, we know little about how medication beliefs are cognitively organised. For example, whether individual beliefs, such as those identified in the studies, described above, can be grouped together into core themes or components in the same way that illness beliefs are structured around five components (Leventhal and Nerenz, 1985). A key question here is the extent to which patients beliefs about medicines in general are differentiated from their beliefs about specific medicines prescribed for their illness. It is of theoretical and practical relevance to gain a better understanding of the nature and extent of the relations between medication beliefs and treatment adherence, particularly to identify which beliefs are associated with nonadherence to medication. Finally, if medication beliefs appear to be related to adherence then there is need to identify some of the salient factors which determine these beliefs.

These questions are clearly beyond the scope of qualitative studies alone as the investigation of the structure and distribution of beliefs requires a method of assessing and scoring beliefs and subsequent statistical evaluation of inter-relations between them. The aim of the experimental section of this thesis was to contribute to existing knowledge by systematically applying quantitative research methodologies to address the above questions. Studies exploring the nature (structure and distribution) of medication beliefs

among patients from a range of chronic illness groups are described in Chapter 7. The effects of medication beliefs on adherence to treatment are evaluated in Chapter 8 and further analyses investigating some of the determinants of medication beliefs are described in Chapter 9. The findings are summarised in Chapter 10 together with an analysis of the possible implication of this work for future research and practice.

CHAPTER 6
Methodology

The literature review, detailed in Chapters 1 to 5 identified a number of outstanding questions concerning the nature, effects and determinants of medication beliefs. The empirical aspect of the thesis attempted to address some of these questions in a series of cross-sectional studies involving patients from a range of illness groups and a sample of university undergraduates. The current Chapter will list the empirical questions addressed within this thesis. This will be followed by an overview of the empirical work to guide the reader through the various studies and analyses addressing the nature, effects and determinants of medication beliefs which are described in Chapters 7, 8 and 9. Further sections will describe the samples and the measures used and the approach to statistical analyses.

6.1 Empirical questions addressed within this thesis

1. What are the main beliefs that patients with chronic illnesses hold about medicines prescribed for them?
2. What are the main beliefs that patients with chronic illnesses hold about medicines in general?
3. How do patients' beliefs about their prescribed medication relate to their beliefs about medicines in general?
4. How are the main specific and general medication beliefs distributed within and across illness groups?
5. What is the nature and extent of the relationship between medication beliefs and adherence to treatment?
6. How do beliefs about specific and general medication vary within and across socio-demographic and cultural groups.
7. How do patients' beliefs about medication relate to their personal experience of the beneficial or adverse effects of medicines?
8. How do patients' beliefs about medication relate to their beliefs about illness.?

An important aspect of the empirical was therefore to identify the 'main' beliefs about medicines. These were conceptualised as the core themes underlying commonly-held beliefs about medicines. The identification of these themes and hence the

conceptualisation of 'main beliefs' is described in Chapter 7. Thus, questions 1-4 relate to the nature of medication beliefs and are addressed in Chapter 7. Question 5 concerns the effects of medication beliefs in relation to adherence behaviours and is addressed in Chapter 8. Finally, questions 6, 7 and 8 refer to the determinants of medication beliefs and these are addressed in Chapter 9.

6.2 Overview of the empirical work:

6.2.1 Rationale for the research strategy

Addressing the research questions outlined above was hampered by the lack of a standard validated tool for assessing medication beliefs. Although Marteau (1990) and Echabe and colleagues (1992) had developed questionnaires which included questions about medicines, these scales elicited views about medication in other contexts rather than focusing in detail on representations of medication. A related problem was to decide *which* particular medication beliefs to focus on. It was possible that peoples ideas about medicines might be many and varied. The review of previous qualitative studies, described in Chapter 5, had identified a number of individual beliefs about medicines which seemed to be common to patients across a range of illness groups. However, these studies had not clarified which were the *main* beliefs that influenced patients' attitudes and behaviour in relation to medicines.

The present studies were among the first to systematically investigate the nature, effects and determinants of medication beliefs in chronic illness. Therefore a primary goal was to identify commonly held beliefs about specific and general medication and then to investigate whether certain beliefs could be grouped together into 'common-themes' which were relevant across various illness groups. If this could be achieved it would facilitate a preliminary investigation of relations between medication beliefs and adherence as attention could be focused on a small number of "common-themes", rather than a large number of individual beliefs.

6.2.2 Plan of the empirical work

The empirical work was carried out in two stages. Stage A was to identify a small number of 'common-themes', which might also be called core-constructs or factors, underlying commonly held beliefs about medication. Stage B was to explore the nature and extent of associations between these core-constructs and other parameters such as reported

adherence or illness beliefs in order to identify the effects and some of the determinants of medication beliefs.

Both stages of the investigation involved the analysis of cross-sectional data. The majority of the analyses were conducted on the **main sample** comprising six illness groups (asthma, diabetes, end-stage renal disease, chronic heart disease, psychiatric out-patients and a sample of inpatients of a general medical ward). Data from this sample was used for the majority of the analyses investigating the nature, determinants and effects of medication beliefs. However, during the course of this thesis several research questions arose which could not be addressed using data from the main sample. It was therefore necessary to recruit auxiliary samples. The **auxiliary samples** comprised oncology patients, undergraduate university students and a sample of patients seeking care from a community pharmacy or homeopathic/herbal practitioners.

Data from the main sample were therefore used for two purposes. First, to derive and validate a Beliefs about Medicines Questionnaire (BMQ). Second to explore interactions between the BMQ and other variables to investigate the determinants and effects of medication beliefs in chronic illness. The empirical work proceeded in 5 steps:

Step 1 Data collection: A pool of items assessing medication beliefs was administered to the main sample at the same time as a battery of questionnaires assessing other relevant constructs. These constructs were chosen on the basis of hypothesised relations with medication beliefs. and included measures of reported adherence to medication and beliefs about illness, detailed in Section 6.4. The medication belief items comprised 34 statements representing beliefs about prescribed medication (*specific* beliefs) and medicines in general (*general* beliefs) as described in Chapter 7.

Step 2 Identifying core-constructs underlying common beliefs about medication: Principal Component Analysis (PCA) of Likert scale responses to the 34 items assessing medication beliefs was used to investigate whether this relatively large number of individual beliefs about medicines could be grouped into a smaller number of factors.

Step 3 Psychometric evaluation of PCA factors as components of a Beliefs about Medicines Questionnaire (BMQ): Evaluation of the psychometric properties of the factors using the data set obtained from the main sample provided a preliminary validation of the PCA

factors as components of a new questionnaire based method for assessing cognitive representations of medication: the BMQ.

Step 4 Using the BMQ to explore the determinants and effects of medication beliefs in chronic illness. These analyses were conducted on the same cross-sectional data set obtained from the main sample from which the BMQ factors had been derived by PCA. Once the broad range of medication beliefs had been simplified into core themes, represented by the BMQ factors, these could be used as a basis for further investigation. Quantitative associations between medication beliefs (BMQ factors) and other variables were used to explore the determinants and effects of medication beliefs in chronic illness. For example the distribution of scores on the BMQ factors was used to explore the distribution of the main medication beliefs within the chronic illness samples. Similarly associations between factor scores and adherence self-report scores were used to explore relations between medication beliefs and adherence. Finally, interrelations between BMQ factors and other variables (such as socio-demographic factors, type of illness and beliefs about illness) were used to identify some of the possible determinants of medication beliefs. Some of the findings provided further evidence for the criterion-related validity of the BMQ.

Step 5 Recruitment of an auxiliary sample. The BMQ was administered to further samples to address the effects of culture on medication beliefs (University undergraduate students), the experience of side-effects as possible determinants of medication beliefs (oncology patients) and to conduct additional tests on the discriminant validity of the BMQ (patients seeking care from a community pharmacy or homeopathic/herbal practitioners).

6.3 Participants

6.3.1 Main sample

The chronic illness groups from which the patients were sampled were chosen to reflect a variety of disease and treatment characteristics. Asthma was chosen as a symptomatic condition with a fluctuating severity. Diabetes was chosen because of its high prevalence and as an example of a severe illness requiring a high degree of self-management by the patient. End stage renal disease (ESRD) was chosen as an example of a life-threatening illness in which medication, although an essential component, is not the mainstay of treatment. Chronic heart disease was selected in view of its high prevalence and because treatment is based on medication. Psychiatric out-patients were chosen because

medication is targeted at psychological rather than physical problems. Finally the general hospital in-patient sample was included to represent a group of patients whose condition had recently deteriorated resulting in admission to hospital.

A further reason for choosing the above range of illness groups was to represent conditions where medication was likely to have differing effects on symptoms. For example, medication often produces clear symptomatic benefit in asthma but patients with chronic heart disease and psychiatric disorders may perceive a more tenuous link between medication and symptomatic benefit and medication may produce little or no perceived effect on symptoms in ESRD. Ethical committee approval was granted for the study in each of the participating clinics and hospitals. The main characteristics of the six samples are shown in Table 6.1 and the individual illness samples are described in more detail below.

Table 6.1 Demographic characteristics of the Main sample

	Asthma Clinic	Diabetic Clinic	Renal Dialysis IP	Cardiac IP	Psychiatric Clinic	General Medical IP
n	78	99	47	120	89	91
Gender (% male)	37	39	49	71	37	50
Age (mean, SD)	45.5 (18.3)	46.6 (18.5)	49 (17.3)	63.6 (12.4)	45.8 (10.9)	54 (19.8)
Educational Experience		*				
Secondary (%)	68.0		59.6	81.4	47.8	71.8
Tertiary (%)	22.7		21.3	11.5	28.4	23.5
Advanced (%)	9.3		19.1	7.1	23.8	4.7
Number of prescribed medicines (mean, SD)	3.5 (1.7)α	#	7.1(1.9)β	3.5 (2.3)β	2.2 (1.4) α	4.1 (3.2)β

* Data unavailable
IP = Hospital In-patient
α = Patient report of number of prescribed medications
β = Number of prescribed medication obtained from the patient's medical notes
The exact number of medicines prescribed for each patient was not recorded. However the majority of patients were prescribed only one medication (Insulin or a single oral anti-hypoglycaemic agent)

6.3.1.1 Asthma Sample

Patients were recruited from the weekly out-patient clinics of two consultant respiratory physicians at Hove General Hospital, East Sussex. The main function of the clinic was to provide a clinical assessment of patients who had previously been admitted to hospital under the care of the consultant respiratory physician or had been referred as an out-

patient by their GP. The clinics therefore catered for patients with a broad range of respiratory disorders and were not targeted specifically at patients with asthma.

During a 3 month sampling period between March and May 1994, the medical notes of all patients scheduled to attend the clinics were examined two weeks prior to the clinic date. Patients whose medical notes specified a diagnosis of asthma of at least 3 months duration and who had been prescribed one or more medicines for regular use over a period of at least two months prior to the study, were included if they could read and understand the study questionnaire. These patients were sent a letter inviting them to take part in a study of patients' views about illness and treatment (The letter is shown in Appendix 1)

On arrival at the clinic, patients informed the receptionist whether or not they wanted to take part in the study. Those who agreed were referred to the researcher who explained the study, elicited demographic details and then asked the patient to complete the study questionnaire while waiting to see the clinic physician. At this stage patients were excluded if they were unable to read the questionnaire because of a poor command of English or due to very poor eye sight.

Of 105 asthma patients on the clinic schedule 17 refused to take part in the study, 9 did not attend the clinic and 1 who agreed to take part subsequently withdrew without completing the questionnaire. Seventy-eight patients the study and completed the clinic questionnaire. The overall response rate was therefore 78/105 = 74.3%.

The demographic characteristics of the asthma sample are shown in Table 6.1. The mean age was 45.5 years (SD=18.3; range 18-87) and the participants, 37% of whom were male, had a range of educational experience (68% secondary, 22.7% tertiary and 9.3% higher). Patients reported that they had been prescribed a mean of 3.5 (SD=1.7) medicines for their asthma. For 96.2% of patients this included an inhaled or oral corticosteroid medication. The mean duration of asthma was 1.6 years (SD 1.3).

Test-retest sample: The asthma sample was also used to assess the test-retest reliability of study measures assessing beliefs about medicines and self-reported adherence to medication. Of 78 repeat questionnaires, 31 were returned giving a test-retest response rate of 40%. The 31 responders were not significantly different from the 47 non-respondents in terms of age, gender, duration of illness or number of medicines prescribed for them.

6.3.1.2 Diabetic sample

Patients were recruited from the hospital out-patient diabetic clinic at Watford General Hospital, London, by a post-graduate student, working under the supervision of the author. Four diabetic clinics were held weekly for newly diagnosed patients; those attending for clinical review, a clinic for pregnant diabetics and a "young diabetic" clinic catering mainly for adolescent patients. As the study was primarily concerned with medication beliefs of adults with chronic illness, data collection focused on the review clinic.

A consecutive sample of attenders at the clinic were recruited over a six week period during April and May 1994. Patients were eligible for inclusion in the study if they had a history of diabetes of greater than 3 months, and had been prescribed one or more medicines for regular use over a period of at least two months prior to the study. Patients were excluded if they were unable to read the study questionnaire because of a poor command of English or due to very poor eye-sight.

During a six week period, 124 study-eligible patients were approached to take part in the study. Twenty patients refused to take part and 104 patients returned the study questionnaire. Five of the study questionnaires were rejected (>5% of responses to questionnaire statements were missing or illegible). The remaining 99 questionnaires were retained for analysis. The final completion rate was 79.8%.

The demographic characteristics of the sample are shown in Table 6.1. The mean age was 46.6 years (SD=18.5; range 20-84) and 39% were male. Sixty four (64.7%) of the patients were insulin-treated while the remaining patients received oral hypoglycaemic medication (tablet-treated). For the purposes of certain analyses, these groups were treated separately. The demographic characteristics of the insulin-treated and tablet-treated patients are shown separately in Table 6.2

Table 6.2 Demographic characteristics of the diabetic sample by treatment type

	Insulin- Treated Diabetic Clinic	Tablet-Treated Diabetic Clinic
n	64	35
Sex (% male)	33	47
Age (mean, SD)	40.4 (18.2)	57.9 (13.0)

The clinic staff wished to keep the demands the research imposed on patients to a strict minimum. For this reason details of current medication and educational experience were not recorded. However, the clinic pharmacist reported that the majority of patients were receiving only one medicine for their diabetes (insulin or a single oral hypoglycaemic agent).

6.3.1.3 Renal Sample

The sample was recruited from the renal unit at St Mary's Hospital London, by a post-graduate student, at the School of Pharmacy University of London, supervised by the author. The aim was to recruit approximately half of the 103 patients on the hospital dialysis list in June, 1994. Patients were eligible for entry if they could read and understand the questionnaire, were well enough to complete it during the dialysis session and had been receiving haemodialysis treatment with at least one associated medication, for at least three months.

The hospital haemodialysis regime comprised three 8-hour dialysis sessions per week. The hospital haemodialysis patients were therefore a fairly 'static' population who attended the clinic at regular intervals. Sampling on the basis of consecutive attendance was judged to be inappropriate as approximately 17 patients would be undergoing dialysis at any given time. Therefore, patients were randomly selected from the dialysis list and evaluated for entry into the study until a sample of sufficient size had been attained. Twenty-one patients whose names were randomly selected from the clinic list failed to meet the entry criteria and were excluded from the study because they had insufficient command of English to read the questionnaire (9), were too unwell to complete the questionnaire (8), or were no longer receiving dialysis on the unit (4). Of 59 study-eligible patients who were randomly selected from the list, 12 refused to take part or did not complete the questionnaire. Forty seven patients (23 male, 24 female) completed the study. Thus out of 59 randomly selected study-eligible patients, 47 completed the questionnaire giving a response rate of 79.7%.

Sixteen (34.0%) had experienced at least one failed renal transplant and 18 (38.3%) were on the waiting list for transplantation at the time of the study. The mean age was 49 years (SD 17.3; range = 20-84) and participants had a variety of educational (59.6% secondary, 21.3% tertiary and 19.1% higher) and ethnic (14.9% Asian, 31.9% Afro-Caribbean and, 53.2% Caucasian), backgrounds. The mean duration of dialysis treatment was 53 months (range 3-216 months) and the mean number of prescribed medicines was 7 (range 3-12).

6.3.1.4 Psychiatric sample

The sample were recruited as part of audit evaluating a medicines-information service at a psychiatric out-patient clinic staffed by a consultant psychiatrist at Brighton General Hospital. Questionnaire items assessing patient's beliefs about medicines and self-reported adherence to medication were included as part of a base-line assessment conducted prior to the provision of a medicines information service. Only data collected during the baseline assessment were included in this thesis. Patients were eligible for inclusion in the study if they had been under the care of local psychiatric services for longer than one year and if their condition was stable enough to be managed on an out-patient basis. Further criteria were that they had been prescribed at least one medication as part of their psychiatric treatment programme for at least 6 months prior to the study and that they were able to read and understand the study questionnaires.

Study-eligible patients, identified from the clinic list and hospital medical notes, were sent a letter, signed by the consultant psychiatrist, inviting them to take part in an audit of a medicines information service (A copy of the letter is included in Appendix 2). Those who accepted were asked to attend a 'research clinic' at the hospital out-patient department where they completed a questionnaire eliciting their views about various types and sources of information about medicines and their satisfaction with medicines information they had received to date. These data provided a baseline assessment for audit of the information service and were not used in the present study. For the purposes of the present study, patients were asked to complete questionnaire items addressing their views about medicines and self-reported adherence to prescribed medication. (The medication belief items and their use in the development of the BMQ are described in Chapter 7. The adherence scale is described in Section 6.4.4 of this chapter). Patients who attended the 'research clinic' received a small payment to cover their travel costs

Pilot study: Items assessing beliefs about medicines were derived from studies which had not involved psychiatric patients. It was therefore necessary to pilot these items on a sub-group of the psychiatric sample. A pilot sample of 10 patients was randomly selected from the study-eligible patients who agreed to take part and were asked to attend the 'research clinic on the first day of the study. Of the 10 patients selected for the pilot sample, 3 failed to attend the 'research clinic'. Although, data collected from this group were not included in subsequent analyses, this sub-sample needs to be taken into account when calculating the response rate.

One hundred and twenty five patients were invited to attend the 'research clinic' 27 failed to attend and 98 patients entered the study. Seven were included in the pilot sample and a further 2 failed to legibly complete over 95% of the questionnaire items. The final study sample therefore comprised 89 patients. Allowing for the 7 pilot study patients, the response rate was 98/125=78.4%.

The demographic characteristics of the final sample (n=89) are shown in Table 6.1. The mean age was 45.8 years (SD=10.9; range 18-87). and the participants, 37.1% of whom were male, represented a range of educational experience (47.7% secondary, 28.4% tertiary and 23.9% higher). Patients reported that they had been prescribed a mean of 2.2 (SD=1.2) medicines for their psychiatric illness the mean duration of which was 10.2 years (SD=8.4). Fifty four percent of the sample were diagnosed as having a psychotic illness and 46% were diagnosed as having a neurotic illness.

6.3.1.5 The cardiac and general medical inpatient samples:

Patients were recruited from general medical wards of two London teaching hospitals and five district general hospitals in London and Brighton, over an 8 week period between January-March, 1995, by seven pre-registration pharmacy students, working under the supervision of the author. The inclusion criteria were:

- patient aged 18 years or over
- patient admitted to the general medical ward with a clear primary diagnosis, for which they had been prescribed one or more regular medicines
- patient judged by nursing staff to be well enough to complete the study questionnaire
- Patient able to read and understand the study questionnaire

Study-eligible patients were identified from a list of new admissions obtained from the nursing kardex or clinical pharmacy log-book, a record of patients and their medication updated on a daily basis by the ward-based clinical pharmacist. Consecutive new admissions were evaluated for inclusion in the study by the pre-registration pharmacist who used the hospital medical notes to identify the primary diagnosis and number of medicines prescribed for the patient and elicited the nurses' assessment of whether the patient was well enough to participate. Of 254 study-eligible patients, 37 refused to take part. and 217 entered in the study. Six of the study questionnaires were rejected (>5% of responses to questionnaire statements were missing or illegible). The remaining 211

questionnaires were retained for analysis. The final completion rate was therefore 211/254= 83.1%.

Separation into cardiac and general medical groups: The final sample obtained from the general medical wards comprised patients from the diagnostic groups shown in Table 6.3.

Table 6.3 Diagnostic profile of the 'cardiac' and 'general medical inpatient' samples

Sample	Primary diagnosis	n	percentage of sample
Cardiac	Chronic cardiac diseases	120	56.8%
General medical inpatients	Chronic respiratory diseases♦	34	16.2%
	Gastro-intestinal disorders	23	10.9%
	Diabetes	21	9.9%
	Cancer	8	3.8%
	Epilepsy	5	2.4%

♦ respiratory patients = asthma/COAD (n=33) and cystic fibrosis (n=1)

Patients with chronic cardiac disease represented the single largest 'diagnostic group' comprising 56.8% of the total sample. In subsequent analyses this group was treated as a single illness group and the remaining patients (n=91) were grouped together as the 'General medical inpatients'. Thus although the cardiac and general medical inpatient samples were obtained from the same source, for the purposes of the present study they were analysed as separate 'illness groups'. The sample characteristics of the cardiac and general medical inpatient samples are shown in Table 6.1 and are described below.

Cardiac sample: The mean age of the sample was 63.6 years (SD=12.4; range 21-86). and participants, 70.7% of whom were male, had a range of educational experience (81.4% secondary, 11.5% tertiary and 7.1% higher). Patients had been prescribed a mean of 3.5 (SD=2.3) medicines for their cardiac condition

General medical sample: The mean age of the sample was 54.0 years (SD=19.8; range 18-86). and participants, 51.1% of whom were male, represented a range of educational experience (71.8% secondary, 23.5% tertiary and 4.7% higher). Patients had been prescribed a mean of 4.1 (SD=3.2) medicines for their primary illness.

6.3.2 Auxiliary samples.

6.3.2.1 Undergraduate students

The sample comprised undergraduate students at the University of Brighton attending the following courses: Pharmacy, Engineering, Accounting and Finance, Social Policy and Administration and Humanities. Permission to invite students to take part in the study was obtained from relevant members of academic staff (e.g. course leaders). Students were approached at the start of a core-lecture and invited to take part in the study by a third year undergraduate pharmacy student, working under the supervision of the author. Those who agreed were given five minutes to complete the study questionnaire before the lecture began. Completed questionnaires were collected by the student-researcher. In most courses, students were split into two main groups for ease of teaching and we aimed to approach at least one group in each year. This was achieved for each year, but about two thirds of students in year 3 of the Accounting and Finance were not eligible for inclusion in the study as they were on placement during the recruitment period. All students who were approached agreed to participate in the study but just over 5% of returned questionnaires were incomplete or spoiled and were omitted with the analysis, leaving a total of 600 completed questionnaires from 635 administered, giving a final response rate of 600/635 = 94.5%. The sample characteristics are shown in Table 6.4.

Table 6.4 Demographic characteristics of the respondents (n=600 undergraduate students)

	number (% of total)
Age	
mean	23.9 years
range	17-37
STD	6.3
Gender	
male	304 (50.4)
Course	
pharmacy	157 (26)
mechanical engineering	122(20)
accounting and finance	135 (23)
social policy and administration	111 (18)
humanities	75 (13)
Year of study	
1	253 (42)
2	208 (35)
3	139 (23)
Experience of taking medication	
current	143 (24)
past	281 (47)
Cultural origin	
Afro-Caribbean/ African	24 (4)
Asian	89 (15)
European	458(76)
Other	29 (5)

Matched Sample: One hundred and sixty participants Asian (n=80) and European (n=80) were matched for age and sex and course as shown in Table 6.5 below.

Table 6.5: Characteristics of the matched sample of Asian and European undergraduate students

	Asian	European
n	80	80
Age [mean (SD)]	22.0 (2.85)	22.1 (2.86)
Gender: number (%) male	39 (48.7%)	39 (48.7%)
University Course		
• Pharmacy	39	39
• Mechanical Engineering	14	14
• Accounting and Finance	23	23
• Social Policy	4	4

6.3.2.2 Oncology patients

The sample comprised consecutive attenders at an oncology out-patient clinic and hospital ward at Guy's Hospital, London over a four week period between December and January 1995-1996. Patients were eligible for the study if they could read and understand the questionnaire and felt well enough to complete it. A total of 100 study eligible-patients were approached and 91 completed the study questionnaire, giving a response rate of 91%. The study sample, recruited from the Oncology out-patient clinic (n=51), and ward (n=40). Comprised 47 males, and represented a range of ages (mean = 58.5 years; range=19-85; SD=15.8), and educational experience (77.2% secondary; 14.2% tertiary and 7.6% higher). All patients were receiving at least one prescribed medication (mean=4.3; range=1-18; SD =2.7; mode=2). The mean time since diagnosis of the present condition was 20 weeks (range 1-249; SD = 34).

6.3.2.3. Allopathic/Complimentary sample: a matched group of patients seeking care from allopathic (community pharmacy) and complimentary sources (homeopathy/herbal clinic)

This sample was recruited in order to compare medication beliefs of allopathic and complementary care seekers. Participants were recruited from a single community pharmacy and a herbal and homeopathic clinic in Brighton. The inclusion criteria are shown in Table 6.6. Patients were recruited over a four week period between January and February 1996.

Table 6.6 Inclusion criteria for the Allopathic/Complementary sample

Allopathic Care (community pharmacy)	Complimentary Care (herbal/homeopathic clinic)
• Presenting a prescription for dispensing at the pharmacy which included at least one medicine intended for regular personal use	• Attending a herbal or homeopathic clinic
• Judged by the pharmacist to be well enough to complete the questionnaire	• Judged by the herbalist/homeopath to be well enough to complete the questionnaire
Able to read and understand the study questionnaire	

Allopathic Care sample: was recruited from a community pharmacy during weekday evenings. Consecutive patients presenting a prescription at a community pharmacy were approached by the researcher while they were waiting for the prescription to be dispensed. One hundred and twenty six study-eligible patients were approached, 22 refused to take part and 104 patients entered the study and returned completed

questionnaires (>90% items answered legibly). The response rate for the Allopathic Care sample was therefore 104/126 = 83%.

Complementary Care sample: was recruited from the clinics of a single herbalist and single homeopath, in Brighton. Both practitioners felt that it would be inappropriate to base a researcher in the clinic and so patients were invited to take part in the study by the herbalist/homeopath. Those who agreed were asked to fill out the questionnaire and return it to the author at the University of Brighton in the stamped addressed envelope provided. Fifty-four questionnaires were given out and 36 completed questionnaires were returned. The final response rate for the Complementary Care sample was therefore 36/53=67.9%

Matched samples: Seventy two participants were matched for age and sex and educational experience. Patients from the Allopathic Care sample were selected to match the age and gender profile of the Complimentary Care group. Matching was carried out because of the large disparity in group sizes and the possible confounding effect of age and gender. The characteristics of the matched samples are shown in Table 6.7 below. There were no significant differences between Allopathic and Complimentary samples in terms of age, and gender. The Complementary Sample had significantly greater educational experience (Pearson Chi-Square = 6.34; DF=2; $p<0.05$) and had made significantly more visits to homeopathic ($t=3.35$; $n=72$; $p<0.001$) and herbal ($t=4.84$; $n=72$; $p<0.001$) practitioners in the 6 months prior to the study than had the Allopathic Care sample. There were no significant differences between the samples in the number of reported visits to NHS General Practitioners or hospital admissions. The latter finding was interpreted as an indicator that the samples were comparable in terms of illness severity.

Table 6.7: Characteristics of the matched sample of recipients of Allopathic and Complimentary care

	Allopathic Care Sample	Complementary Care Sample
n	36	36
Age [mean (SD)]	42.3 (11.1)	47.3 (18.6)
Gender: number (%) male	9 (25)	8 (22)
Educational Experience		
Secondary (%)	66.6	44.4
Tertiary (%)	16.7	16.7
Advanced (%)	16.7	38.9
Mean (SD) number of visits over previous 6 months to:		
• General practitioner	2 (1.8)	1.7 (1.9)
• Homeopath	0.03 (.17)	0.78 (1.33)
• Herbalist	0	1.5 (1.9)
Mean (SD) Number of hospital admissions over previous year	0.36 (1.1)	0.19 (0.58)

6.4 Measures

Where validated instruments could be found in the literature these were used or adapted. However, few instruments had been developed to assess medication-related cognitions. Thus part of the empirical work entailed the development and use of measures designed for the study. These ranged from simple single item statements to more psychometrically sophisticated scales. In particular, the empirical work resulted in the development of the 18 item Beliefs about Medicines Questionnaire which is described in detail in Chapter 7 and a four item Reported Adherence to Medication (RAM) scale which is described in this section 6.4.4.

It was not possible to administer all the measures detailed below to all of study samples. Rather, specific questions were addressed in particular illness groups. This was necessary because for some illness samples, there were restrictions on the number of questionnaire items. For example the psychiatric sample patients were also being asked to complete questionnaires relating to another study as described above. The questionnaire administered to the hospital inpatient samples was kept as brief as possible in order not to place excessive demands on patients who were likely to be feeling more unwell than those attending out-patient clinics.

6.4.1 The Illness Perception Questionnaire (IPQ) (Weinman et al, 1996)

The IPQ comprises five scales measuring the five components of illness representation specified in Leventhal's self-regulatory model of illness (Leventhal et al, 1980). The five scales assess *identity* (the symptoms the patient associates with the illness), *cause* (personal ideas about aetiology), *time line* (the perceived duration of the illness), *consequences* (expected effects and outcome), and *cure/control* (beliefs about potential for cure and control i.e. how one controls or recovers from the illness). The psychometric properties of the IPQ have been evaluated in 7 patient groups including asthma, diabetes and hospital haemodialysis recipients (Weinman et al, 1996). The internal consistency, test-retest reliability and the concurrent, discriminant and predictive validity of the IPQ scales are within acceptable limits (Weinman et al, 1996). The full IPQ with instructions to subjects is shown in Appendix 3. The scoring methods for the five scales, together with examples of scale items are as follows.

The *Identity* scale is comprised of 12 core symptom items that the patient is asked to rate for frequency on a four point scale (4= all of the time, 3= never, 2=occassionally and 1=never), according to how often each symptom is experienced *as part of* the patient's illness. This core list of items may be added to by researchers to tailor the scale to specific illnesses. For example in the IPQ administered to the asthma sample, 4 additional symptoms were added: tight chest, panic attacks, depression and anxiety. The *Identity* scale score was obtained by summing the scores obtained for the individual items. High scores indicate more severe symptomology and a strong illness 'identity'

The items from the four other IPQ scales are presented in a mixed order and rated by the patient on a five point scale (1=strongly disagree, 2= disagree, 3 = neither agree nor disagree, 4 = agree and 5= strongly agree) After reverse scoring the appropriate items, scores for the *Time-line* (3items e.g. *'My illness will last a long time')*, *Consequences* (7 items e.g. *'My illness is a serious condition')* and *Cure/Control* (6 items e.g. *'My illness will improve with time')* scales are obtained by summing all the scale items and dividing by the number of items.

For the *Cause* scale it is not appropriate to sum all of the items as each item represents a specific causal belief. In the present study, patients beliefs about the cause of their illness were assessed in two ways. The degree of endorsement of each of the 8 possible causes included in the IPQ (chance, other people, genetic, stress, diet, pollution, own behaviour, germ or virus) was assessed by the degree of agreement with relevant IPQ statement (e.g. "*My illness was inherited*") scored on a linear scale from 1 = strongly disagree to 5 = strongly agree. Additionally the total number of causal attributions endorsed by the patient was computed. Endorsement of a causal belief was indicated by an agree/strongly agree response to the individual causal item. Each item endorsed was given a score of 1. Thus the total number of causal attributions made by the patient was obtained by summing the scores from 0-8. The present study was conducted before publication of the IPQ and an early version of the question was used by permission. Subsequently, two further casual belief items were added to the IPQ during its development. Thus the *Cause* scale in the published questionnaire comprises 10 items while the version used in the present study was limited to 8 items (see Appendix 3 for details). In the most general version of the IPQ, each item refers to "illness" In the present study this was replaced with the name of the patient's illness (e.g. diabetes, asthma etc.) as recommended by Weinman et al, 1996.

6.4.2 Beliefs about control over illness

These were assessed using a modified version of a the Perceived Control Over Recovery scale (Partridge and Johnston, 1989). The wording of scale items was altered so that questions related to perceived present and future control over a named illness (e.g. asthma or diabetes). The 'asthma' version is shown in Appendix 4. Identical items were administered to the dialysis sample, except that the phrase "my asthma" was replaced by "my kidney condition". Item responses were scored on a 5-point Likert scale, where 1 = strongly disagree to 5 = strongly agree. Response scores for individual variables were summed to give a Perceived Control Over Illness score, with high scores indicating stronger beliefs in internal control over the illness.

Note: In the version of this measure administered to the asthma group an additional item was used to assess the extent to which control over asthma was attributed to medication This was assessed on the basis of Likert scale responses to a single item statement: *"Whether my asthma gets better or worse depends on how well my medicines work"*, scored from 1 = strongly disagree to 5 = strongly agree where high scores indicate a stronger belief that control over asthma depends on medication. The item was included with the Perceived Control Over Illness Scale but was analysed separately.

6.4.3 Perceived lack of empathy from medical and nursing staff (PLE)

This was assessed by responses to the statement "*Doctors and nurses do not know how it feels to have asthma*", scored on a 5-point Likert scale where 1= strongly disagree and 5=strongly agree. This statement was included as an additional item in the IPQ section of the study questionnaire but was analysed separately.

6.4.4 Reported Adherence to Medication (RAM) scale

Published adherence self-report scales were thought to be unsuitable because they are not specific to medication (DiMatteo et al, 1993, Kravitz et al, 1993) or because they do not elicit self-report of the frequency of adjusting or altering dosages (Morisky, 1986). A reported adherence to medication scale (RAM) was therefore devised for the present study. This was a four-item composite self-report scale which assess two aspects of adherence behaviour. The study requires a means of assessing both active non-adherence (AnA) (e.g. tendency to deliberately alter the dose of medication) and passive non-adherence (PnA) (e.g. the tendency to forget to take medication). See Section 1.6 for a

fuller explanation of these terms. Non-adherence was indicated by the tendency to forget to take medication and to deliberately adjust or alter the dose from that recommended by the physician. The RAM scale comprises four adherence statements. Two items are scored on a 5-point Likert scale. A further two items are phrased as direct questions asking the patient to report the frequency of adjusting or forgetting medication (scored on a 5-point scale where 1=never and 5=very often). A total medication adherence score is obtained by summing responses to each of the four individual items. Scores ranged from 4 to 20, with higher scores indicating greater non-adherence. The items are shown in Table 6.8

Table 6.8 The reported adherence to medication scale (RAM)

- *I sometimes forget to take my medicines*
- *I sometimes alter the dose of my medication to suit my own needs*

Item responses were scored on a Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree

- *Some people forget to take their medicines. How often does this happen to you?*
- *Some people I have talked to say that they miss out a dose of their medication or adjust it to suit their own needs. How often do you do this?*

Item responses are scored as 1 = never, 2 = rarely, 3 = sometimes, 4= often and 5 very often.

In an attempt to diminish the social pressure on patients to under-report non-adherence, adherence questions were phrased in a non-threatening manner and patients were assured that their responses to all questionnaire items were anonymous and confidential. In order to limit "ordering effects" (Abraham and Hampson, 1995), adherence items were located in separate sections of the questionnaire and were immediately preceded by statements about medicines phrased in a positive or neutral way (e.g. "Whether I feel better of worse depends on my medicines" "My medicines make me feel better"). The way in which adherence items appeared in the context of items assessing medication beliefs can be seen in Appendix 5 which provides an example of the study questionnaire.

The internal reliability of the RAM scale was evaluated using the Main sample. The Cronbach alpha coefficients for each illness group are shown in Table 6.9. The insulin treated and tablet-treated diabetic patients were considered separately because the RAM scale is scored differently for insulin adherence as described below.

Table 6.9 Cronbach alpha values as a measure of internal consistency of the RAM scale

Sample	n	Cronbach's alpha
Asthma clinic	78	0.60
Psychiatric clinic	89	0.73
General-medical IP	90	0.67
Cardiac IP	116	0.67
Dialysis IP	47	0.83
Diabetes: Insulin treated*	64	0.73
Diabetes Tablet treated	35	0.50

*2-item scale (see below)

Table 6.9 shows that the RAM scale has acceptable internal reliability in all but one of the illness groups. The low value obtained in the Tablet-treated diabetic patients indicates that the scale should be used with caution in this group.

The test-retest reliability of this scale was evaluated in parallel with the BMQ factors in the sample of asthma patients (n=31) described in Section 6.3. Spearman correlation between RAM scores over a two week interval indicate that the test-retest reliability of the scale was within acceptable limits (rho=0.72; n=31; $p<0.001$).

6.4.4.1 Reported adherence to insulin (RAI scale)

The appropriate self-management of insulin entailed the regular adjustment of dosage in response to diet and glucose testing. For these patients, adherence was indicated by a composite scale comprising the two items assessing the frequency with which insulin dosage was adjusted. The Cronbach alpha for these two items in the insulin-treated sample was acceptable (0.73) and justified their incorporation into a 2-item scale assessing the reported frequency of adjusting the dosage of insulin. In order to facilitate ease of comparison between the RAI scale and the RAM scale described above, scores on each of the items was reversed and the total score for the 2-item scale was doubled to create a scale range of 4-20 with higher scores indicating greater non-adherence.

6.4.4.2 Using the RAM scale to separately assess Active and Passive non-adherence

The passive and active aspects of adherence assessed by the RAM scale can be analysed as separate 2-item constructs. Passive nonadherence (PnA) construct is assessed by combining the two items concerning 'forgetting' medication. Scores range from 2-10 with higher scores indicating more frequent forgetting. The active nonadherence (AnA) scale is

computed by summing scores on the two items eliciting patients' self report of how often they adjusted or altered the dose of their asthma medication outside the physicians recommendations. Scores on the AnA scale thus range from 2-10 with higher scores indicating more frequent adjusting.

6.4.5 Self-Rated Heath

This was a 7-item self-rated health scale adapted from the Medical Outcomes Study Short Form Questionnaire (SF-36) which has been validated for use in abroad range of illness groups (Jenkinson et al. 1994; Ware, Jr. and Sherbourne, 1992). The scale items and scoring methods are shown are shown in Appendix 6. A Self-Rated Heath score is computed by summing the scores obtained on the individual items, after reversing scores on the appropriate items. Scale scores range from 7 to 35 with high scores indicating perceptions of better health. The scale was used only in the asthma sample. It had an acceptable degree of internal consistency with a Cronbach alpha value of 0.84 in the asthma sample.

6.4.6 Perceived effect of prescribed medication on symptoms (PEMS)

This was assessed using two items:

- *Whether I feel better or worse depends on my medicines*
- *My medicines make me feel better*

Responses to each statement were scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree.
Scores obtained for the individual items were summed to produce a Perceived Effect of Medication on Symptoms Scale (PEMS). PEMS scores ranged from 2 to 10 with higher scores indicating a greater perceived effect of medication upon symptoms.

This PEMS was administered to only two illness groups within the main sample: the cardiac and general medical inpatient groups. Although the internal reliability of the scale was fairly low - Cronbach alpha coefficients were 0.58 and 0.55 for the cardiac (n=120) and general medical samples (n=91) - this scale was used because an alternative validated measure could not be found in the literature.

6.4.7 The Sensitive Soma (SS) Scale

The Sensitive Soma Scale (SS) assesses perceptions of personal sensitivity to the potential adverse effects of medication. The scale is currently under development at Rutgers University New Jersey, USA (Howard Leventhal personal communication, 1995) The SS comprises five items, shown below, which assess *abstract* ideas about general sensitivity to medication and the past *experience* of adverse symptoms which are perceived to be associated with medicines usage.

- *My body is very sensitive to medicines.*
- *My body over-reacts to medicines.*
- *I usually have stronger reactions to medicines than most people.*
- *I have had a bad reaction to medicines in the past.*
- *Even very small amounts of medicine can upset my body.*

Responses to the individual items are scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree. Scores on the 5 individual items are summed to give a total sensitive some scale score from 5 to 25 where high scores = high perceived sensitivity to the potential adverse effects of medication: This *Sensitive Soma* scale was administered to the cardiac (n=120) and general medical in-patient (n=91) samples. The internal reliability of the scale, as measured by Cronbach's alpha, was high in both groups (general-medical = 0.80; cardiac = 0.78).

6.4.8 Single measures assessing medication-related cognitions

Two single item statements were used to assess certain medication-related cognitions. They were included in addition to 34 single items representing commonly held beliefs about medication, as shown in Appendix 5.

Satisfaction with amount of medicines information received

This was assessed by responses to the single statement:

- *I have been given enough information about my medicines*

Responses were scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree

Lack of trust in prescribed medication

This was assessed by responses to the single statement:

- *I cannot always trust my medicines*

Responses were scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree

6.4.9 Educational Experience

Patients experience of formal education was assessed by asking them to state their age on finishing full-time education. Responses was coded on a scale of 1 to 3 where: 1= Secondary (finished at age 16 or below); 2=Tertiary (finished between 17 and 20 years old); and 3=Higher (finished at an age 21 years or greater).

6.5 Procedure

Each participant was invited to take part in a study of patients' views about their illness and treatment. The researcher stressed that the study was being conducted by the University and was completely independent of the hospital in order to avoid any response bias which might have resulted if patients had associated the researcher with the clinical team. Patients were told that their responses were confidential and anonymous and it was stressed that the completed questionnaires would not be seen by any of the staff involved in their care. The instructions to participants - shown in the Appendix 5 - included a description of explanation of how the term 'medicines should be interpreted in the questionnaire.

Clinic patients were asked to complete the questionnaire while waiting to see the doctor. Patients recruited from the ward (the cardiac and general medical patients form the main sample and the oncology patients from the auxiliary sample) were asked to complete the study questionnaire by the researcher who then arranged to collect it at a convenient time.

6.6 Approach to statistical analyses

Data were analysed using the SPSS Windows 6.1 statistical software package (Norusis, 1992). A variety of parametric and non-parametric techniques were used. Details of the specific statistical procedures are provided in the Methods section of each study described in Chapters 7,8 and 9. The present section provides an overview of the rationale for the choice of statistical approaches.

The data obtained from the measurement scales used were considered to be **ordinal** in character, which is usually thought to preclude parametric statistical procedures such as factor analysis, multiple regression, t-test or ANOVA & ANCOVA. However, several investigations of the robustness of these procedures to violations of the parametric assumptions have demonstrated that these procedures may be used with ordinal data if certain conditions are met (Glass & Hopkins,1984).

With respect to the t-test, ANOVA and ANCOVA procedures, it has been demonstrated (Boneau 1960; Hsu & Feldt 1969) that for a t-test with $n>15$, the true level of significance deviated from nominal (i.e. $p<0.05$) by less than 1%, even with extremely skewed or uniform distributions. Similarly, Glass et al. (1972) have demonstrated that non-normality of data does not seriously affect the true significance level (e.g. the error was rarely greater than a few percent). With respect to correlation coefficients, on which the factor analysis and multiple regression procedures rely, Glass & Hopkins (1984) report that, with a large n, Pearson's r and Spearman's Rho differ by as little as 0.01 (see Appendix 7 for an example using the data from this study). Hence the data were considered adequate for factor analysis and multiple regression where $n>100$. For the individual correlations between measures reported, where for some groups $n<100$, Spearman correlations where used throughout for consistency and to allow meaningful comparisons between coefficients.

Principal Components Analysis, was used to identify latent variables or factors underlying items assessing beliefs about medication. Multivariate factor analytic techniques such as PCA , are sensitive to outliers in the data. Therefore cases were checked for outliers on all relevant variables using the Mahalanobis distance (Tabachnik & Fidell 1993). Cases were excluded if the Mahalanobis distance was greater than 3 SD from the mean. A more detailed discussion of the Principal Components Analysis is provided in Chapter 7.

Where comparisons were made between matched sample the Independents groups t-test was used and not the Matched pairs test (Glass & Hopkins, 1984).

Missing data: Cases with missing data for the variables being analysed were omitted list-wise (Norusis, 1992). In this method a case is eliminated from the analysis if it has a missing value for a variable in the list which is being analysed. Thus, for some of the analyses reported, it will be seen that there are minor inconstancies in the sample sizes

reported for different analyses conducted on the same sample. This is due to the fact that cases with missing data were eliminated from the analysis.

CHAPTER 7
The nature of medication beliefs

This chapter describes a series of analyses exploring the nature of medication beliefs of chronically ill patients. The analyses address four of the broad empirical questions mentioned in Section 6.1, namely:

1. What are the main beliefs that patients with chronic illnesses hold about medicines prescribed for them?
2. What are the main beliefs that patients with chronic illnesses hold about medicines in general?
3. How do patients' beliefs about their prescribed medication relate to their beliefs about medicines in general?
4. How are the main specific and general medication beliefs distributed within and across illness groups? (i.e. What proportion of people hold these beliefs and how strongly are they held?).

These questions were addressed by a series of analyses identifying the main specific and general medication beliefs and developing a method for eliciting an scoring them. The analyses are grouped in three sections. Sections 1 and 2 describe the process of identifying some of the main medication beliefs and the subsequent development of a novel method for assessing beliefs about medication: the Beliefs about Medicines Questionnaire BMQ. Section 1 shows how the items comprising the BMQ were derived using Principal Components Analysis (PCA) to identify the themes or factors underlying commonly held beliefs about prescribed medication (specific beliefs) and about medicines in general (general beliefs). Section 2 deals with the evaluation of the psychometric properties of the BMQ. Finally, Section 3 describes the use of the BMQ factors to explore the distribution of medication beliefs within and between illness groups.

The rationale for the approach was that the main medication beliefs which patients hold could be identified by examining how these beliefs were cognitively organised. If commonly held medication beliefs could be reduced to a few coherent factors which were consistent and stable across illness groups, then these factors could be said to represent 'core themes' of medication representations. The items loading on them could be thought of as the *main* medication beliefs held by chronically ill patients.

7.1 Using Principal Components Analysis (PCA) to identify core-themes underlying commonly held beliefs about specific and general medication

A series of PCA was performed to address the following specific research questions

1. Can commonly held beliefs about prescribed medication be reduced to simple factors which are stable across illness groups ?
2. Can commonly held beliefs about medicines in general be reduced to simple factors which are stable across illness groups ?
3. To what extent are representations of medication prescribed for personal use cognitively differentiated from ideas about medication in general?

Questions 1 and 2 were addressed by seeing whether PCA factors identified in a sample of patients with one chronic illness could be replicated if the same items were administered to a sample of patients with a different illness. Question 3 was addressed by investigating whether the factors underlying specific and general medication beliefs could be replicated if their constituent specific and general items were entered into a single PCA. If the original specific and general factor structures were replicated this would suggest that patients' beliefs about prescribed medication and medicines in general were quite well differentiated. Three sets of PCA were performed to address questions 1,2 and 3 in turn. The method and results for each analysis are described in sequence. This is followed by a general discussion of the findings from the three sets of analyses.

7.1.1 Analysis 1: PCA of beliefs about medicines prescribed for personal use (Specific)

The aim of this analysis was to test the hypothesis that patients' representations of their personal prescribed medication are structured around common themes. In order to accept this hypothesis representational structures identified in one diagnostic group would have to be stable across various illness groups. Thus a factor structure identified by PCA in one diagnostic group should remain consistent if factor items were administered to other diagnostic groups and subjected to a further PCA.

7.1.1.1 Method

Participants The cardiac, asthma, renal and general medical inpatient samples described in Sections 6.3.1.1, 6.3.1.3 and 6.3.1.5.

Measures A pool of 34 items representing commonly held beliefs about specific and general medication. The items were derived from beliefs identified from the literature which appeared to be common to patients with a range of chronic illnesses. A further series of interviews were conducted with 35 patients receiving regular medication for chronic illness (20 haemodialysis patients and 15 patients with myocardial infarction) in an attempt to identify common beliefs which had not emerged in previous studies. Patients were asked open questions eliciting their views about medicines prescribed for them and their thoughts about medicines in general. This resulted in the pool of 34 items shown, together with their origin, in Table 7.1. Responses to each statement were scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4 = strongly agree and 5 = strongly agree. The items and instructions to participants are shown in Appendix 5

NB Only the 16 specific medication beliefs were used in the exploratory PCA of specific beliefs described in this section. Items dealing with beliefs about medicines in general were entered into a separate PCA described in Section 7.1.1.2

Principal Component Analysis (PCA) Items were entered in a PCA setting Eigenvalue=1 and using the non-orthogonal (OBLIMIN) method of rotation. Cases with missing data were deleted listwise as described in Section 6.6. A non-orthogonal method of rotation of factors was chosen in preference to an orthogonal method such as Varimax because the latter technique has been criticised on the grounds that "forcing" variables into orthogonal relationships in an attempt to provide clean and simple factors may obscure important interactions between them (Kline, 1994). Conversely, non-orthogonal techniques such as Direct Oblimin allow factors to rotate more freely. Although, this makes it more difficult to identify separate factors it is thought that this technique is appropriate for the analysis of variables which are likely to be related in the real world, such as beliefs, attitudes or personality attributes (Cattell, 1995). Extraneous items were omitted on the basis of the Kaiser Meyer Olkin (KMO) statistic for each item, factor scree plot and final factor loading as described below (Norusis, 1992).

Table 7.1 Pool of Medication Statements Subjected to PCA including details of source

STATEMENTS ABOUT SPECIFIC MEDICATION PRESCRIBED FOR THE PATIENT	Source
My health, at present, depends on medicines	1
Having to take medicines worries me	2,3,4
My life would be impossible without medicines	1
My medicines are powerful	1
Without medicines I would be very ill	1
I sometimes worry about the long-term effects of my medicines	3,5
My medicines are a mystery to me	1
My medicines are effective	1
My medicines disrupt my life	2,6,7
I sometimes worry about becoming too dependent on my medicines	2,3,8
My health in the future will depend on medicines	1,9
My medicines protect me from becoming worse.	1,2
I would like to change my present treatment	1
It is difficult for me to take my medicines in exactly the way my doctor told me	1
I can cope without my medicines	1,2
I am in control of my medication	2,10

STATEMENTS ABOUT MEDICINES IN GENERAL	Source
Without medicines doctors would be less able to cure people	1
Newer medicines are more effective than older ones	1
Most medicines are addictive	3
People who take medicines should stop their treatment for a while every now and again	2,3
Medicines only work if they are taken regularly	1
Medicines do more harm than good	5
Medicines are not natural remedies	1,3,4, 8,11,12
All medicines are poisons	4
It is better to do without medicines	1,2,4,8
Natural remedies are safer than medicines	1,3,4,8,11,12,13
Stronger medicines are more dangerous than weaker medicines	14,15
Medicines are a necessary evil	4,13
Doctors place too much trust on medicines	1,16
If doctors had more time with patients they would prescribe fewer medicines	1,16
There is a big difference between a medicine and a drug	13,16
The medicine you get is more important than the doctor you see	1
Doctors use too many medicines	1,5,16
Most medicines are safe	1

1. Interviews conducted with 35 chronically ill patients
2. Conrad,1985
3. Morgan & Watkins, 1988
4. Fallsberg, 1991
5. Clinthorne etal,1986
6. Becker et al, 1978
7. Cochran & Gitlin, 1988
8. Donovan & Blake, 1992
9. Arluke, 1980
10. Helman,1988
11. Coulter, 1985
12. New & Senior, 1991
13. Gabe & Lipshitz-Phillips, 1982
14. Lorish,1990
15. Leventhal, 1986
16. Rees-Jones, 1979

Extraneous items were omitted in two stages. First, the Kaiser Meyer Olkin (KMO) statistic was computed for each item. The KMO statistic of an individual item is a measure of the amount of variance in that item which can be explained by combinations of all other items within the group and is essentially a measure of the degree to which a particular item "belongs" with the others. Items with a KMO statistic of <0.7 were rejected as recommended by Norusis (1992). Items with a KMO statistic of >0.7 were retained and re-entered into a second PCA using non-orthogonal (OBLIMIN) rotation and list-wise omission of cases with missing values. Further items were omitted if they had a low or diffuse loadings on the factors identified by scree plot analysis (Norusis, 1992). In order to eliminate the influence of multi-dimensional outliers, items retained within the final factor structure were cleaned by removal of multivariate outliers (Mahalanobis distance >3 standard deviations from the multi-dimensional mean) and removal of cases with greater than five missing items (Tabachnick & Fidell, 1993).

Procedure: The analysis was performed on responses to the 16 items representing beliefs about prescribed medication (*Specific*), shown in Table 7.1 above. The responses from the cardiac sample (n=120) were analysed first. In order to test whether the factor structure obtained in the cardiac group could be replicated in other illness groups, a further series of PCA was carried on the responses to factor items obtained from the asthma, renal and general medical inpatient samples. The reason for limiting initial exploratory factor analysis of *specific* items to a single illness group was that the way in which people view medication prescribed for a particular illness may, to some extent, depend on the nature of that illness. Thus we could not assume that patients with one chronic illness perceive their medication in the same way as those with another. The cardiac sample was chosen for initial analysis on the grounds that it was the single largest diagnostic group within the main sample.

7.1.1.2 Results: PCA of specific medication beliefs

Responses to the 16 items eliciting beliefs about prescribed medication (Specific beliefs shown in in Table 7.1), obtained from the cardiac sample (n=120), were entered into exploratory PCA. The mean and SD for each of the 16 items is shown in Appendix 8 An initial 4-factor structure was obtained which accounted for 53% of the variance but was not meaningful. Four items with KMO values < 0.7 were omitted and these are shown in Table 7.2. The remaining 12 items were re-entered into the analysis. setting Eigenvalue =1. A screen plot analysis, suggested a 2-factor solution explaining 47.3% of the variance.

Omission of two items (*"I can cope without my medicines"*; *"My medicines are effective"*), which had a low loading spread across both factors resulted in a two factor solution explaining 53% of the variance.

Table 7.2 Items omitted on the basis of low KMO scores

ITEM	KMO STATISTIC
My medicines are powerful	0.58
It is difficult for me to take my medicines in exactly the way my doctor told me	0.66
I would like to change my present treatment	0.51
I am in control of my medication	0.69

Having arrived at a core structure of two 5-item factors the data set was cleaned by removal of multivariate outliers (Malanobis distance >3 standard deviations from the multi-dimensional mean) and removal of cases with greater than five missing items. This resulted in omission of 6 cases. Re-factoring on the 114 cases remaining produced a similar two factor structure explaining 51% of the variance.

Factor labels The final 2-factor structure is shown in Table 7.3. Items were grouped in a logically consistent factor structure. The first factor comprised items relating to the positive effect of medication on health and were representative of the perceived necessity of medication for maintaining health. This factor was labelled *Specific-Necessity*. The second factor comprised items relating to concerns about the adverse consequences of medication based on beliefs about the potential for dependence or harmful long-term effects and that medication taking is disruptive. This factor was labelled *Specific-Concerns*.

Table 7.3 Factor structure obtained by principal components analysis of BMQ-Specific items (n = 114* patients with chronic heart diseases)

STRUCTURE MATRIX: with non-orthogonal (OBLIMIN) rotation	Factor 1 Specific-Necessity	Factor 2 Specific-Concerns
My life would be impossible without my medicines	**.81**	-.06
Without my medicines I would be very ill	**.78**	.09
My health, at present, depends on my medicines	**.71**	-.02
My medicines protect me from becoming worse	**.67**	-.19
My health in the future will depend on my medicines	**.62**	-.11
I sometimes worry about the long term effects of my medicines	-.00	**.80**
Having to take my medicines worries me	-.18	**.78**
I sometimes worry about becoming too dependent on my medicines	-.19	**.72**
My medicines disrupt my life	.05	**.67**
My medicines are a mystery to me	-.00	**.58**
Eigenvalue	**2.8**	**2.4**
Percentage variance explained	**28.5**	**24.0**

* 6 cases were removed during the cleaning procedure.

Replication of factor structure PCA of the 10 items retained within the 2-factor structure obtained in the cardiac sample were cleaned as detailed above and entered into a PCA with non-orthogonal (OBLIMIN) rotation. The 2-factor structure was replicated by PCA of the responses to the 10 items obtained from asthma, renal and general medical inpatient samples (asthma: cleaned cases = 72, haemodialysis: cleaned cases = 41 and general medical inpatients n =90). The factor structure obtained for each of the samples contained identical items, although minor differences in individual factor loadings. The factor loadings obtained for the asthma, renal and general medical inpatient samples are shown in Appendix 8.

7.1.1.3 Discussion

The findings indicate that a simple, stable factor structure had been obtained. Replication of the structure in different illness samples suggests that the factors represent 'core themes' underpinning common representations of prescribed medication. Moreover the results show that the individual belief items loading on the factors are some of the 'main' beliefs which chronically ill patients hold about their prescribed medication.

The core constructs relating to medication prescribed for the patient were: beliefs about the necessity of the medicines for maintaining health (*Specific-Necessity*) and concerns about medication (*Specific-Concerns*). The *Specific-Necessity* construct is a cognitive representation of the perceived role of medication in protecting against deterioration of the present and future health status of the patient. It is interesting that the item "*My medicines are effective*" was not retained on this factor due to diffuse loading. This is contrary to expectations since beliefs about efficacy seem to be implicit within the *Specific-Necessity* construct. The reason for this finding may lie in patient's conceptions of 'efficacy'. For example, an "effective" medicine may be one which cures completely. Thus a medication which prevents deterioration of an already compromised health status, may be necessary or even essential but not effective. Further work is needed to explore this in more detail.

The *Specific-Concerns* construct comprises aspects of both emotional (*eg "Having to take my medicines worries me*") and cognitive ("*My medicines are a mystery to me*") representation and thus may provide access to both aspects of the parallel processing described by Leventhal in the SRM (Leventhal et al, 1980)

These preliminary findings obtained by PCA of specific beliefs will be discussed in more detail in Section 7.1.4 which provides a general discussion of the results obtained for the PCA of specific and general beliefs and the PCA of combined of specific and general items

7.1.2. Analysis 2: PCA of Beliefs about medicines in general (General)

7.1.2.1 Method

Participants The 6 chronic illness groups comprising the main sample described in Section 6.3:

Measures The 18 items dealing with beliefs about medicines in general included in the poll of 34 items representing commonly held beliefs about specific and general medication. Described in Section 7.1.1. and shown in Table 7.1

Principal Component Analysis (PCA) was performed as described in Section 7.1.1

Procedure: The rationale for limiting initial exploratory factor analysis of specific items to a single illness group did not apply to beliefs about medicines in general. Here, the aim was to explore representations of medication as a broad concept , rather than beliefs which might be unique to a particular illness group. In an attempt to obtain a factor structure which was representative of patients with a range of chronic illnesses, data obtained from three diagnostic groups (asthma, diabetes and haemodialysis) were amalgamated and subjected to an exploratory PCA. The reason for selecting these particular diagnostic groups for combination was that the cardiac and general hospital samples were derived from the same population of hospital in-patients. Data was combined in order to investigate themes underlying beliefs about medicines in general which would be common across chronic illness populations. Thus combining the cardiac and general medical inpatient samples may have reduced the 'scope' of the sample. The factor structure obtained from the amalgamated data set (asthma, diabetes, renal samples) was verified by investigating the extent to which the structure could be replicated when the factor items were entered in 3 separate PCAs using data from the individual cardiac, general medical and psychiatric samples.

7.1.2.2 Results: PCA of General medication beliefs

Eighteen items (shown in Table 7.1) eliciting beliefs about medicines in general were entered into exploratory PCA in combined sample (n=224) of asthma (n=78), diabetic (n=99) and renal patients (n=47). The mean and SD for each of the 18 items is shown in

Appendix 9. A factor structure could not be obtained within 25 rotations. Elimination of 8 items, shown in Table 7.4 below, which had a low KMO statistic (<0.7) and setting a two factor solution as suggested by scree plot analysis, resulted in a 2-factor solution explaining 49% of the variance.

Table 7.4 Beliefs about medicines in general items rejected on the basis of a low KMO statistic (<0.7)

ITEM	KMO Statistic
Without medicines doctors would be less able to cure people	0.57
Newer medicines are more effective than older ones	0.52
Medicines only work if they are taken regularly	0.51
Stronger medicines are more dangerous than weaker medicines	0.69
Medicines are a necessary evil	0.68
There is a big difference between a medicine and a drug	0.51
The medicine you get is more important than the doctor you see	0.54
Most medicines are safe	0.61

Two items with low or diffuse factor loadings were omitted ("*It is better to do without medicines*"; "*Medicines are not natural remedies*"). Entry of the 8 remaining items into PCA, setting Eigenvalue = 1, produced a 2-factor solution in 7 iterations, explaining 49% of the variance. Cleaning the data by removal of 5 cases (Malanobis distance >3 standard deviations from the multi-dimensional mean and cases with greater than five missing items) increased the variance explained to 53%. The final factor structure is shown in Table 7.5.

Table 7.5 Factor structure obtained by PCA of BMQ-General items (n = 219 patients with chronic illnesses-asthma = 77, diabetes = 99, haemodialysis recipients = 42)*

STRUCTURE MATRIX: Principal components analysis with non--orthogonal (OBLIMIN) rotation.	Factor 1 General-Overuse	Factor 2 General-Harm
If doctors had more time with patients, they would prescribe fewer medicines	**.80**	.11
Doctors use too many medicines	**.79**	.15
Doctors place too much trust in medicines	**.72**	.24
Natural remedies are safer than medicines	**.70**	.33
Medicines do more harm than good	.33	**.72**
People who take medicines should stop their treatment for a while every now and again	.18	**.70**
Most medicines are addictive	.02	**.70**
All medicines are poisons	.28	**.69**
Eigenvalue	**2.8**	**1.5**
Percentage variance explained	**35.3**	**19.0**

* Five cases were removed during the cleaning procedure

Factor labels The first factor comprised items expressing beliefs about the way in which medicines are used by doctors. The essence of this factor, labelled *General-Overuse* is the notion that medicines are over-prescribed by doctors who place too much trust in them. The second factor, labelled *General-Harm* concerns the potential of medication to harm. Representations of medication as harmful, addictive, poisons appears on the same factor as the belief that people who take medicines should stop their treatment every now again.

Replication of factor structure The factor structure was confirmed on cleaned data from the cardiac group (n=116) and the psychiatric outpatients (n=86) as shown in Appendix 9. The factor structure obtained for the cardiac, psychiatric and combined (asthma, diabetes, renal) samples contained identical items, although there were minor differences in individual factor loadings. PCA of the data from the General Medical in-patients, produced a similar factor structure, with the exception of one item: "*Natural remedies are safer than medicines*" which had migrated from factor 1 to factor 2 as shown in Table 7.6.

Table 7.6 Factor structure obtained by PCA of data from the General Medical In-patient sample (n=90)

STRUCTURE MATRIX: Principal components analysis with non--orthogonal (OBLIMIN) rotation.	Factor 1 General-Harm	Factor 2 General-Overuse
Most medicines are addictive	**.71**	-.15
Medicines do more harm than good	**.68**	-.12
Natural remedies are safer than medicines	**.65**	-.18
All medicines are poisons	**.57**	-.10
People who take medicines should stop their treatment for a while every now and again	**.43**	-.34
If doctors had more time with patients they would prescribe fewer medicines	.12	**-.84**
Doctors use too many medicines	.19	**-.74**
Doctors place too much trust on medicines	.22	**-.72**
Eigenvalue	**2.33**	**1.42**
Percentage variance explained	**29.1**	**17.8**

7.1.2.3 Discussion

A simple, stable factor structure was obtained. The fact that the PCA factor structure obtained in the combined sample was replicated on two other illness samples suggests that the factors represent 'core themes' underlying common representations of medicines in

general. However, an exact replication of the factor structure was not obtained in the general medical inpatient sample indicating that the *General-Harm* factor may have low stability. This is discussed in more detail in Section 7.2 when the psychometric properties of the factors are evaluated as components of the Beliefs about Medicines Questionnaire (BMQ).

The arrangement of individual beliefs to form core representations of medicines in general merits comment at his stage. The item "M*edicines do more harm than good*" had a high loading on the *General-Harm* factor. The importance of this concept in treatment cognitions is reinforced by an earlier study in which a similar Likert scale statement, "*Medicines do as much harm as good*", was the highest loading item on a factor representing Negative attitudes towards the profession of medicine, which included beliefs about doctors, medicines and doctors' use of diagnostic tests and investigations (Marteau, 1990).

Furthermore it is notable that the item *"People taking prescribed medication should stop their treatment every now and again"* is linked with a representation of medication as essentially harmful, addictive poisons. The phenomenon of deliberately stopping medication was noted by Morgan and Watkins (1988) in their qualitative study of British hypertensive patients some of whom explained this activity as being necessary to avoid becoming too dependent on or addicted to the medicines. The fact that these items factor together is indicative of a coherent and complex representation of medication - the harmful effects of medication are increased if it is taken continuously and so one should give the body a break every now and then.

Considering the *General-Overuse* representation it may appear surprising that the belief that "*Natural remedies are safer than medicines*" loads on this factor, as this statement seems to relate to the intrinsic nature of medicines rather than the way in which they are used. However, for all but one of our samples this item was associated with the *General-Overuse* construct. A possible explanation is that this construct represents a concept of treatment which is essentially anti-medication and pro "natural remedies". In this representation the belief that medication is overused by doctors is consistent with the view that natural remedies as less harmful and implicitly more favourable than medicines. This may be analogous to the first cluster obtained by Echabe and colleagues in their study of illness and medication representations in which, health was represented as a balance between body and mind and medicines were viewed negatively (Echabe et al. 1992).

Although the clear factor structure obtained in all but one of the samples supports the inclusion of this item in the *General-Overuse* factor, the fact that, in one sample, this item migrated to the *General-Harm* factor warrants further investigation, and this is discussed in more detail later in Section 6.4..

The absence of a "benefit" dimension

At first sight it may surprising that both general factors contain items relating to aspects of medication which are essentially negative. A coherent "benefit" dimension did not emerge from our original items. This may be because the items we used were not representative of an underlying dimension of "benefit". Alternatively, it may simply be that a clear representation of benefit is obscured by strong beliefs about the potential for harm. It is salient that in most of the studies from which the source items were derived, the benefit of medicines was often taken for granted. People who had generally negative views about medication tended to cite the potential for harm, rather than the lack of "efficacy" or "benefit" as a focus for their concerns about medication (Conrad, 1985; Morgan and Watkins, 1988) and other authors have remarked on this (Britten, 1994).

At first sight, the representations of medicines in general described above seem to amount to a rather negative view of medicines as harmful and overused by doctors. However, it is important to bear in mind that this does not necessarily mean that most people see medicines in this way. People can disagree with the statements on each factor and so express a view of medication as essentially safe and appropriately used. The main point here is that PCA has shown that certain beliefs link together to form coherent core representations. In other words people seem to organise their ideas about medicines (addiction, poison, harm, regular long term use) into coherent themes or components. Although the specific content will vary between individuals (e.g. one sees medicines as harmful and addictive, another thinks they are generally safe and non-addictive), the components are consistent.

7.1.3 PCA of combined Specific and General factor items

This analysis was designed to addressed the question of whether ideas about personal prescribed medication (Specific) and medicines in general occupy separate cognitive dimensions. This was tested by combining the items loading on the Specific and General factors and entering them in a single PCA. The degree to which items separated into their original factors could be used as indicator of the stability of the factors. It would also serve

as a preliminary investigation of the extent to which patients tended to distinguish between medication prescribed for them and medicines in general. A high degree of separation between general and specific items would indicate that patients made clear distinctions between specific and general medication.

7.1.3.1. Method

Participants The 6 chronic illness groups comprising the main sample described in Section 6.3:

Measures The 18 items loading on the 4 factors obtained by PCA of specific and general medication beliefs described in Sections 7.1.1 and 7.1.2 above. The psychiatric and diabetic samples had originally received only 16 and 15 and of these items. Although they received identical General items as the other illness groups , they received a slightly different set of Specific belief items as shown in Table 7.7 below. The set of Specific beliefs items (16 in total) administered to the psychiatric sample differed by one item and from that administered to the asthma, cardiac, renal and general medical samples (shown in Table 7.1). The set which the diabetic patients received differed by two items. The items concerned are shown in Table 7.7 below

Table 7.7 Differences in the pool of Specific medication belief administered to the psychiatric and diabetic samples (see table 7.1 for the full set of items)

Item omitted from the pool	Item replacing it
Psychiatric sample (n=89)	
• *Without my medicines I would be very ill'*	• *Only my medicines can control my mental health problems'*
Diabetic sample (n=99)	
• *My life would be impossible without my medicines'* • *My medicines protect me from becoming worse'*	• *My insulin* controls my diabetes* • *Insulin prevents my blood sugar from becoming low*

* For tablet-treated diabetic patients the term 'insulin' was replaced 'medicines'

The above difference in the item pools arose from limitations of space within the study questionnaire. In an effort to investigate issues which were thought to be particularly pertinent to the diabetic and psychiatric diagnostic groups, they received a slightly different set of Specific medication items from those administered to other illness samples.

Principal Component Analysis (PCA) was performed as described in Section 7.1.1

Procedure Data from all six illness groups comprising the main sample was pooled. Responses to the 18 items loading on the final general and specific factors described above were combined and entered into a PCA with non-orthogonal (OBLIMIN) rotation, setting a 4-factor solution. As mentioned above the psychiatric and diabetic samples had not received two of the items loading on the Specific-Necessity construct. Thus, items which were unique to these groups (shown in Table 7.7) were omitted from the analysis and replaced with the mean score of the remaining items loading on the *Specific-Necessity* factor.

7.1.3.3 Results of PCA of combined Specific and General factor items

PCA of pooled data from all 6 illness samples showed a clear separation of Specific and General items. A 4-factor structure was obtained which closely resembled the original Specific and General factor structures except that one item from the *Specific-Concerns* factor '*My medicines are a mystery to me*', loaded marginally higher on the *General Harm* (0.55) than on *Specific-Concerns* (0.39). The factor structure obtained in shown in Appendix 10. Removal of the General Medical sample (n=90) from the data set followed by a further PCA on pooled data from the discreet diagnostic groups (asthma, diabetes, renal, cardiac and psychiatric) yielded the factor structure shown in Table 7.8. which replicated the original Specific and General factor structures.

7.1.3.4 Discussion of PCA of combined Specific and General items

The separation of items into the original factor structures offers preliminary support to the notion that pateitns ideas about specific and general medication are well differentiated. The apparent instability of one item '*My medicines are a mystery to me*' may be an artefact limited to the general medical sample. However, studies are necessary to clarify this point.

Table 7.8 Structure matrix obtained by PCA on combined items from the Specific and General medication belief factors*

	ITEM S refers to medicines prescribed for a specific illness G refers to medicines in general	Factor 1 **Specific Concerns**	Factor 2 **Specific Necessity**	Factor 3: **General Harm**	Factor 4 **General-Overuse**
S	Having to take this medicine worries me	**.83**	-.04	.16	.23
S	I sometimes worry about becoming too dependent on my medicines	**.79**	-.02	.15	.24
S	I sometimes worry about the long term effects of my medicines	**.77**	.05	.19	.14
S	My medicines are a mystery to me	**.49**	-.19	-.01	.33
S	My medicines disrupt my life	**.39**	.19	.11	.36
S	My health, at present, depends on medicines	.03	**.79**	-.05	-.09
S	My life would be impossible without medicines	.03	**.77**	-.14	-.07
S	My health, in the future, will depend on medicines	-.05	**.74**	-.09	-.01
S	Without medicines I would be very ill	-.03	**.67**	-.12	.07
S	My medicines protect me from becoming worse	-.08	**.47**	-.29	-.08
G	Most medicines are addictive	.14	-.11	**.84**	.11
G	Medicines do more harm than good	.09	-.12	**.77**	.17
G	All medicines are poisons	.24	-.15	**.73**	.19
G	People who take medicines should stop their treatment for a while every now and again	.15	-.18	**.63**	.35
G	If doctors had more time they would prescribe fewer medicines	.16	-.02	-.01	**.70**
G	Doctors place too much trust in medicines	.24	-.03	.29	**.68**
G	Doctors use too many medicines	.17	.01	.25	**.67**
G	Natural remedies are safer than medicines	.34	-.13	.22	**.62**
	Eigenvalue	3.6	2.5	1.7	**1.4**
	Percentage variance explained	20.0	14.0	9.4	**7.6**
	Cumulative percentage variance explained	20.0	34.0	43.4	**51.0**

*(pooled data from asthma, diabetic, renal cardiac and psychiatric samples n=433)

7.1.4 General discussion of PCA results

The key finding of the three PCA analyses was the attainment of a simple factor structure for general and specific beliefs about medication. Although differences in the Eigenvalues and the factor loadings of individual items were observed in different data sets, these were as expected when using an iterative technique such as PCA (Cattell, 1995; Kline, 1994). Moreover, variations in Eigenvalue and factor loadings did not change the interpretation of the factors. Items loading on the individual factors were related in a logically coherent way and the factors could be easily labelled. The identification of core dimensions of specific and general representations of medication provided an insight into how patients from a range of chronic illness groups were thinking about medication. However, a number of outstanding questions arise from the limitations of this study.

Limitations of the findings and implications for future research

The purpose of this study was to establish whether it was possible to identify discreet dimensions in the cognitive representation of medication prescribed for personal use and medicines in general. The stability of the factor structure described above suggests that this was achieved. However, at this stage, it is worth pausing to consider the limitations of PCA as a method of establishing the components of cognitive representation. PCA and factor analytic techniques are designed to identify underlying factors which account for the observed correlation between items. The aim is to obtain simple factor structures comprising "core" items which are stable across data sets. In order to achieve a simple structure, several interesting items were omitted from the analysis. The items were derived from interviews with patients and are thus beliefs which are held by at least some people. Thus the factors identified by the PCA described above are core dimensions rather than the only components of medication representation. These issues were discussed in more detail in Chapter 10.

A further limitation of this study is that *Specific* statements related to the prescribed regimen as a whole rather than the individual medicines. The participants were being asked to provide a composite view of their treatment as a whole. The fact that no patients reported difficulty or reluctance in doing this, may indicate a tendency to form a "composite view of prescribed medication". However, we do not know how such a view is formed or the degree to which patients' beliefs about *Specific-Necessity* and *Specific-Concerns* vary between individual components of the regimen. Thus an important question which was not addressed in this preliminary study is whether patients form beliefs which are specific to individual medicines (e.g. aspirin) or types of medication (e.g. analgesics) and how such beliefs might relate to the core dimension of Necessity and Concerns. For example, patients may have concerns about particular medicines which are distinct from the beliefs about dependence, long-term effects and disruption which comprise the *Specific-Concerns* dimension. One example may be the notion that analgesics loose their efficacy if taken regularly for long periods of time (Donovan and Blake, 1992; Lorish et al. 1990).

The discovery of core dimensions of medication beliefs leads us to question the extent of inter- and intra-individual variation in these constructs and whether they are related to other key variables such as illness beliefs and behaviours such as adherence to treatment. Furthermore, a basic question concerns the determinants of these core beliefs. For example, to what extent are they influenced by the socio-demographic characteristics of

the patients or by beliefs about illness. These issues are addressed in more detail in Chapters 8 and 9.

PCA identified core dimensions underlying beliefs about medication which are common to patients from several diagnostic groups and across a range of age and educational characteristics. The isolation of a simple, stable, 4-factor structure provides a focus for further investigations. The following section details the evaluation of the psychometric properties of these factors as components of the Beliefs about Medicines Questionnaire (BMQ).

7.2 Development of the Beliefs about Medicines Questionnaire (BMQ)

The Principal Component Analyses described in the previous sections served two purposes. The first was to increase our understanding of the way in which representations of medication are cognitively structured. A second was to simplify the range of medication beliefs, reported in the literature and identified in interviews with patients, into core themes to form the basis of a questionnaire-based method for the quantitative assessment of representations of medication. The core factors identified by PCA were therefore used to compile an 18-item Beliefs about Medicines Questionnaire (BMQ) which provided an assessment tool for further studies investigating the distribution and effects of medication beliefs in chronic illness, described in Chapters 8 and 9. This section presents psychometric data for the BMQ.

7.2.1 Description of the Beliefs about Questionnaire (BMQ)

The BMQ comprises the items loading on the final 4 factors, obtained by PCA of the 34 statements assessing specific and general medication beliefs, as described in the previous section. The questionnaire is therefore split into two sections.

(a) The BMQ-Specific assesses patients' beliefs about medication prescribed for personal use in the treatment of their particular illness and comprises two 5-item scales assessing personal beliefs about the necessity of prescribed medication for maintaining health (*Specific-Necessity*) and concerns about prescribed medication arising from beliefs about long-term adverse effects, the potential for dependence and the disruptive effects of taking medication (*Specific-Concerns*).

(b) The BMQ-General comprises two 4-item scales which deal with more general views about medicines as a whole. The *General-Overuse* scale addresses views about the way in which medicines are used by doctors and assesses personal beliefs about the extent to which doctors place too much emphasis and trust in medicines and that natural remedies are a safer alternative. The *General-Harm* scale assesses beliefs about the nature of medicines and the degree to which they are perceived as harmful, addictive poisons which should not be taken for long periods of time.

The BMQ items are shown in Table 7.9.

7.2.1.1 Scoring system for the BMQ

Respondents indicate their degree of agreement with each individual statement about medicines on a 5 point Likert scale, where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree. Scores obtained for the individual items within each scale are summed to give a scale score. Thus total scores for the BMQ-Specific scales (*Specific-Necessity* and *Specific-Concerns*), range from 5 to 25. The BMQ-General scales (*General-Overuse* and *General-Harm*) range from 4 to 16. Higher scores indicate stronger beliefs in the concepts represented by the scale.

Factor scores were obtained by summing scores for the individual items loading on the factor to form an ordinal scale. The resultant scores gave an indication of the strength of belief in the dimension represented by the factor with high scores indicating stronger beliefs. A further method for differentiating between individuals on the basis of their medication beliefs was that those obtaining scores above the mid-point value of the scale could be said to be in general agreement with the concepts represented by the statement. BMQ-Specific scores range from 5-25. BMQ-General scores range from 4-20.

Table 7.9 The Beliefs about Medicines Questionnaire (BMQ), showing scale items

BMQ-SPECIFIC -assesses beliefs about prescribed medication	
Specific-Necessity	Specific-Concerns
Beliefs about the necessity and efficacy of medicines prescribed for specific condition	Concerns about the harmful effects of medicines prescribed for specific condition
• *My health in the future will depend on my medicines* • *My health, at present, depends on my medicines* • *My life would be impossible without my medicines* • *Without my medicines I would be very ill* • *My medicines protect me from becoming worse*	• *Having to take my medicines worries me* • *I sometimes worry about the long-term effects of my medicines* • *I sometimes worry about becoming too dependent on my medicines* • *My medicines are a mystery to me* • *My medicines disrupt my life*
BMQ-GENERAL **- assesses beliefs about medicines in general**	
General-Overuse	General-Harm
Beliefs that medicines in general are over-used by doctors	Beliefs that medicines in general are harmful addictive poisons
• *If doctors had more time with patients they would prescribe fewer medicines* • *Doctors use too many medicines* • *Doctors place too much trust on medicines* • *Natural remedies are safer than medicines*	• *Most medicines are addictive* • *Medicines do more harm than good* • *People who take medicines should stop their treatment for a while every now and again* • *All medicines are poisons*

7.2.2 Rationale for the evaluation of the BMQ

The BMQ factors, derived in Study 1, represented constructs which could be easily measured by summing Likert scale responses scores obtained for each item loading on a particular factor (Kline, 1994), to obtain a composite factor score. A quantitative evaluation of the psychometric properties of the questionnaire could thus be conducted on the basis of inter-relations between factor scores and other variables.

Reliability: Before the BMQ scales could be used as a basis for further exploration of the nature, determinants and effects of medication beliefs, it was necessary to demonstrate two aspects of reliability. The scales should have an acceptable *internal consistency* demonstrating that the items loading on each factor related to a single construct as well as acceptable *test-retest reliability*.

Criterion-Related Validity: Due to the lack of validated instruments for assessing medication beliefs concurrent validity was evaluated on the basis of associations between BMQ scales and other single items assessing views about prescribed and general medication. The assessment of the criterion-related validity of each of the BMQ scales was based on the following hypotheses:

Specific-Necessity:

1. Strong *necessity* beliefs would be negatively correlated with 'Perceived ability to cope without medication'. Thus *Specific-Necessity* scores would be negatively correlated with scores on the item: *'I can cope without my medicines'*).
2. Beliefs in the necessity of medication would be related to perceptions of illness. In particular, patients who believed that their illness would last a long time and who experienced more symptoms would have stronger beliefs in the necessity of the medication prescribed to treat it. Thus *Specific-Necessity* scores would be positively correlated with scores on the Identity and Timeline components of the IPQ (described in section 6.4.1) which respectively assess perception of symptom severity and likely duration of the illness.

Specific-Concerns

1. Patients with stronger concerns about their prescribed medication would be more distrustful of it. Thus scores on the *Specific-Concerns* scale would be positively correlated with scores on the *'Lack of trust in prescribed medication'* measure described in Section 6.4.8.
2. Patients with stronger concerns about their prescribed medication would be more likely to want more information about it as information seeking may be a common response to illness-related anxiety (Weinman, 1990). Thus scores on the *Specific-Concerns* scale would be negatively correlated with scores on *the 'Satisfaction with amount of medicines information received'* measure described in Section 6.4.8.
3. Patients with stronger concerns about their prescribed medication would be more likely to want to change their treatment. Thus scores on the *Specific-Concerns* scale would be positively correlated with scores on the *'Desire to change present treatment'* item shown in Table 7.10 below.
4. Patients who perceived themselves to be susceptible to potential adverse effects of medication would have stronger concerns about medication prescribed for them. Thus scores on the *Specific-Concerns* scale would be positively correlated with scores on *the*

'Sensitive Soma Scale' described in Section 6.4.8, which assess perceptions of personal sensitivity to the adverse effects of medication

General-Harm

1. A belief that medicines in general are intrinsically harmful would be positively associated with the view that it is better to avoid taking them. Thus scores on the *General-Harm* scale would be positively correlated with scores on the *'It is better to do without medicines'* item shown in Table 7.10 below.
2. Patents who believed that medicines in general are intrinsically harmful would be more inclined to the view that they could cope without them. Thus scores on the *General-Harm* scale would be positively correlated with scores on the *'I can cope without my medicines'* item shown in Table 7.10 below.
3. Patients who believed that medicines in general are intrinsically harmful would be more likely to consider themselves to be susceptible to potential adverse effects of medication. Thus scores on the *General-Harm* scale would be positively correlated with scores on *the 'Sensitive Soma Scale'* described in Section 6.4.8, which assess perceptions of personal sensitivity to the adverse effects of medication

General-Overuse

1. Patents who believed that medicines in general are overused by doctors would be more inclined to the view that they could cope without them. Thus scores on the *General-Overuse* scale would be positively correlated with scores on the *'I can cope without my medicines'* item shown in Table 7.10 below.
2. A belief that medicines in general are overused by doctors would be positively associated with the view it is better to avoid taking them. Thus scores on the *General-Overuse* scale would be positively correlated with scores on the *'It is better to do without medicines'* item shown in Table 7.10 below.

Discriminant Validity: The discriminant validity of the BMQ-Specific scales was tested on the basis of their ability to distinguish between different illnesses and hence treatment modalities. The discriminant validity of the BMQ-General scales was tested on the basis of their ability to distinguish between patients presenting a personal prescription at a community pharmacy and those seeking complementary therapies. The specific hypotheses were as follows:

Specific-Necessity

Specific-Necessity scores would be influenced by the type of treatment typically prescribed for the illness. The characteristic effects of medication on symptoms may be particularly important . For example, diabetic patients who fail to take their treatment may become severely ill very quickly. Asthma medication often produces symptom relief which the patient can clearly relate to taking of the medication. Similarly, omitting medication may quickly result in adverse symptoms. Conversely, patients receiving medication for mental health related problems may perceive a much more tenuous link between their medication and concrete benefit in terms on symptoms. Thus it was hypothesised that:

1. *Specific-Necessity* scores would discriminate between patients from different diagnostic groups. In particular, diabetic patients would have higher scores than asthma patients who in turn would have higher mean *Specific-Necessity* scores than psychiatric out-patients

Specific-Concerns

Asthma treatment often incorporates corticosteroids. This is a large group of compounds, some of which may produce adverse side effects. Additionally, other members of this group are frequently misused in sport. In short, this class of drugs has a high "media-profile" and patients' concerns could be influenced by this, particularly if they fail to differentiate between steroids they are taking for asthma (which are generally inhaled and therefore less "dangerous") and more potent formulations upon which media attention is often focused. Similarly, psychiatric out-patients are often treated with "tranquillisers", which have received adverse media attention (Cohen, 1983). Thus it was hypothesised that:

1. *Specific-Concerns* scores would discriminate between patients from different diagnostic groups. In particular, asthma and psychiatric patients would have higher mean *Specific-Concerns* scores than other illness groups.

General-Harm and *General-Overuse*

People who believe that medicines in general are intrinsically harmful substances which are overused by doctors may be more inclined to seek care alternative methods of treatment.

1. The hypothesis used to test the discriminant validity of the BMQ-General scales was that people seeking care from a homeopathic or herbal clinic would have higher mean scores on the *General-Harm* and *General-Overuse* scales than those presenting a personal prescription for dispensing by a community pharmacist

7.2.3 Method used for the validation of the BMQ

Participants

- The 6 chronic illness groups comprising the main sample described in Section 6.3.
- The Allopathic/Complementary care sample described in section 6.3.2.3.

Measures

- The Beliefs about Medicines Questionnaire (BMQ), described in section 7.1.
- The Illness Perception Questionnaire (IPQ) (Weinman et al, 1996- see Section 6.4.1)
- Measures of medication-related cognitions, shown in Table 7.10 above.
- Satisfaction with amount of medicines information received, described in Section 6.4.8.
- Lack of trust in prescribed medication, described in Section 6.4.8.
- The Sensitive Soma scale described in Section 6.4.7.

The psychometric evaluation of the BMQ utilised three of the single item statements from the original 34-item pool described in section 7.1.1. The items had not loaded on the BMQ factors and so did not represent a Specific-Necessity, Specific-Concern, General-Harm or General-Overuse cognition. However, they seemed, at face value, to represent interesting medication related cognitions as shown in Table 7.10. and so were retained for further analysis.

Table 7.10 Items assessing medication-related cognitions which were retained for further analysis

Item for original pool (see Table 7.1)	Medication-related cognition which item assess
• *I would like to change my present treatment*	Dissatisfaction with present treatment
• *I can cope without my medicines*	Perceived ability to cope without prescribed medicines
• *It is better to do without medicines*	General reluctance to use medicines

It was thought that these items could be used to test the criterion-related validity of the BMQ factors. For example, a belief that one can cope without a medicine is likely to arise from a rather complex cognitive process involving beliefs about illness, and perceived self-efficacy as well as beliefs about the medicine itself. (Thus this item is clearly not just a *medication* belief). However, it seems likely that a patient's perception of their ability to cope without a medicine would be related to their belief in the *necessity* of that medication. Thus the 'Perceived ability to cope without prescribed medication' construct could be used

to test the Criterion-related validity of the Specific-Necessity factor as in the following section. Three psychometric properties of the BMQ were evaluated. These were reliability, criterion-related validity and discriminant validity.

Procedure

It is important to note that much of the psychometric evaluation presented here, was conducted on the same data set from which the questionnaire was derived and which was subsequently used for further analyses investigating the distribution and effects of medication beliefs. The psychometric evaluation was conducted on the basis of interactions between the BMQ factors and the above measures which had been administered to the main sample at the same time as the pool of mediation belief items from which the BMQ was derived.

The Allopathic/Complementary Care sample were recruited after the BMQ had been derived from the main sample (as detailed in Chapter 6). Only the 8-item BMQ-General (comprising the *General-Overuse* and *General-Harm* scales) was administered to this sample. The *Sensitive Soma* Scale was not available when the asthma, diabetic, renal and psychiatric samples were recruited. The scale was however available when the cardiac and general medical samples were recruited a few months later. Thus different samples were used to evaluate different psychometric properties.

- The internal reliability of the scales was evaluated for all 6 illness groups comprising the main sample
- Test-retest reliability was evaluated using the asthma sample. Repeat questionnaires were sent to the patient, together with a stamped addressed envelope, two weeks after they had been seen in clinic.
- Criterion-related validity of the BMQ-Specific scales was evaluated using the asthma sample, except for interaction between the *Specific-Concerns* and Sensitive Soma scales which were evaluated using the general medical inpatient samples
- The discriminant validity of the BMQ-Specific scales was evaluated in the main sample
- The discriminant validity of the BMQ-General scales was evaluated in the Allopathic/Complementary Care sample.

Statistical techniques

- The internal consistency of the BMQ scales was evaluated using Cronbach's alpha
- The test-retest reliability was evaluated on the basis of Spearman correlations between initial and repeated test scores for each scale.
- The hypotheses for criterion-related validity of the BMQ factors were tested using Spearman (rho) correlation coefficients.
- Differences between BMQ- Specific and General scores across illness samples were assessed using a series of one-way analysis of variance (ANOVA), followed by post-hoc Tukey's HSD test. Multivariate analysis of variance (MANOVA) was not used for analysis of differences in measures due to the moderate level of intercorrelation between *Specific-Concerns* and *General-Harm* (rho=0.31; n=524; p,0.01) and *General-Overuse* (rho=0.24; n=524; p,0.01).
- Differences in mean BMQ-General scores between Allopathic and Complementary care seekers was assessed using an Independent samples t-test. A single tailed test was used as the direction of association had been specified within the relevant hypothesis.

7.2.4. Results

7.2.4.1 Reliability and scale intercorrelation

Cronbach alpha values obtained for each of the diagnostic group are shown in Table 7.11. These data indicate that both the BMQ-Specific and the BMQ-General scales have satisfactory internal consistency, with the exception of the *General-Harm* scale in three of the diagnostic groups.

Table 7.11 Internal consistency (Cronbach alpha) for the BMQ scales and test-retest correlations

	Asthma Clinic (n=78)	Diabetes Clinic (n=99)	Renal Haemo-dialysis (n=47)	Cardiac in-patients (n=116)	Psychiatric out-patients (n=89)	General medical in-patients (n=90)	Test-retest Asthma patients (n=31)
Specific-Necessity	0.80	0.74†	0.55	0.76	0.74‡	0.86	0.77*
Specific-Concerns	0.75	0.80	0.73	0.76	0.63	0.65	0.76*
General-Overuse	0.74	0.80	0.77	0.74	0.73	0.60	0.60*
General-Harm	0.47	0.66	0.83	0.51	0.70	0.51	0.78*

* p<0.001
The diabetes and psychiatric out-patient samples completed shortened versions of the *Specific-Necessity* scale (†4 items; ‡3 items)

As previously described, the psychiatric and diabetic samples were not used included in the PCA from which the BMQ-Specific scales were derived as they had received a slightly different pool of items assessing specific beliefs (see Section 7.1.3.1 for details). As both the psychiatric and diabetic samples had received all the items which subsequently comprised the Specific-Concerns scale Cronbach alpha values could be calculated for this scale. However, only 3 of the 5 *Specific-Necessity* items were included in the original item-pool administered to the diabetic sample and 4 of the 5 were included in the pool originally administered to the psychiatric sample. Therefore, for the psychiatric and diabetic samples Cronbach alpha values were calculated for a 3 and 4-item *Specific-Necessity* scale respectively. A total of 31 of the asthma (n=78) returned the repeat questionnaires, giving a 40% response rate. The correlation coefficients shown in Table 7.11 indicate that the test-retest reliability of the scales is within accepted limits.

7.2.4.2 Criterion-related validity

Specific-Necessity

1. Evidence for the criterion-related validity of the *Specific-Necessity* scale was provided by the negative correlation between scale scores and responses to the statement : *"I can cope without my medicines"* (rho = -0.44; n = 78; $p<0.001$) as expected.
2. The hypothesis that patients who believed that their illness was a chronic condition and those who reported more severe symptoms would have stronger beliefs in the necessity of their asthma medication was confirmed by positive correlations between *Specific-Necessity* scores and scores on the IPQ *Timeline* (rho = 0.49; n = 77; $p<0.001$) and *Identity* (rho = 0.24; n = 76; $p<0.05$) scales which measure perceived duration and subjective symptomatology of the illness.

Specific-Concerns

1. The hypothesis that patients with stronger concerns about their prescribed medicines would be more distrustful of it was confirmed by the positive correlation between the *Specific-Concerns* scale and the statement: *'I cannot always trust my medicines'* (rho = 0.33; n= 78; $p<0.005$)
2. The hypothesis that *Specific-Concerns* would be associated with a desire for more information about medicines was confirmed by the significant negative correlation between the *Specific-Concerns* scale and the statement: *'I have been given enough information about my medicines'* (rho = -0.45; n = 78; $p<0.001$)

3. The hypothesis that *Specific-Concerns* would be associated with dissatisfaction with treatment was confirmed by significant positive correlation between *Specific-Concerns* scores and responses to the statement: *"I would like to change my present treatment"* (rho = 0.37; n = 78; p<0.001).
4. As hypothesised, significant positive correlation were obtained between *Specific-Concerns* and beliefs about personal sensitivity to the adverse effects medication as assessed by the Sensitive-Soma scale (rho = 0.5, n= 91, p<0.001)

General-Harm and *General-Overuse*

1. Correlation between *General-Harm* scores and responses to a single item statement *"It is better to do without medicines"* was as expected.
2. Responses to the statement "*I can cope without my medicines*" correlated, in the predicted direction, with both the *General-Harm* (rho = 0.23; n = 77; p<0.05) and *General-Overuse* scales (rho = 0.34; n = 78; p<0.005).
3. Correlations between the *General-Harm* and *Sensitive-Soma* scales (rho = 0.25, n= 91, p<0.05), although small in magnitude, were in the predicted direction and statistically significant.

7.2.4.3 Discriminant Validity

BMQ-Specific scales

Table 7.12 shows the results of a series of one-way analysis of variance (ANOVA), followed by post-hoc Tukey's HSD test in which mean scores on the BMQ scales were compared across illness samples. It can be seen that the BMQ scales were able to distinguish between patients on the basis of illness (and treatment) groupings. The hypothesis for discriminant validity of the *Specific-Necessity* scale were confirmed by the finding that diabetic group had significantly higher *Specific-Necessity* scores than all other groups and the asthma patients had significantly higher scores than the psychiatric outpatients who attained the lowest mean as predicated.

As was expected, the asthma and psychiatric samples had significantly higher *Specific-Concerns* than the other illness groups, supporting the discriminant validity of this scale.

Table 7.12 Scale means and standard deviations for BMQ scales for the six illness groups comprising the main sample

Scale	Asthma n=78	Diabetes n=99	Renal n=47	Cardiac n=116	Psychiatric n=85	General Medical n=86	F df= 5,505	p
Specific-Necessity								
Mean	19.67_{b}	21.26_{a}	$19.45_{b,c}$	$18.72_{b,c}$	17.72_{c}	19.65_{b}	11.73	<0.01
SD	3.23	2.98	2.78	3.02	3.75	3.92		
Specific-Concerns								
Mean	15.76_{a}	12.91_{c}	$13.77_{b,c}$	13.95_{c}	$15.60_{a,b}$	$14.26_{a,c}$	7.49	<0.01
SD	4.09	3.38	4.28	3.73	3.36	3.92		
General-Harm								
Mean	10.24_{a}	9.29_{a}	9.91_{a}	9.98_{a}	9.92_{a}	9.86_{a}	1.29	0.26
SD	2.30	2.43	3.76	2.32	2.81	2.80		
General-Overuse								
Mean	$11.64_{a,b}$	11.43_{a}	$12.66_{a,b}$	12.80_{b}	$12.25_{a,b}$	$12.42_{a,b}$	3.48	0.01
SD	2.59	2.77	3.19	2.90	2.84	2.76		

Note: Means sharing a common subscript are not significantly different by HSD test (p>0.05).

BMQ-General scales

As was hypothesised, patients attending Complementary clinic (Homeopath/herbalist) had significantly higher scores on both the *General-Overuse* and *General-Harm* scales than those presenting a personal prescription for dispensing at a community pharmacy,as shown in Table 7.13.

Table 7.13 Group differences in BMQ-General scores for matched samples of orthodox and complementary patients

Measure		Allopathic (n=36)	Complementary (n=36)	t (df=70)	p (1-tailed)
G-Overuse	Mean	12.44	16.56	5.89	<0.001
	SD	3.26	2.62		
G-Harm	Mean	10.75	11.85	1.94	0.029
	SD	2.61	2.20		

7.2.5 Discussion

Measures of internal consistency and test-retest reliability of the BMQ were encouraging as was the criterion-related and discriminent validity data. Expected correlations were obtained between BMQ scale scores and other measures of illness and medication beliefs and between *Specific-Concerns* and self-reported adherence to medication. The BMQ scales were able to distinguish between different illness groups/treatment modalities, between particular adherence behaviours and between users of allopathic and complimentary therapies.

The scope of this evaluation is limited by the fact that the BMQ was not compared against other validated measures of medication beliefs. In the absence of such measures, single item constructs of attitudes to specific and general medication were used to test criterion-related validity. Although, the relationships between BMQ sub-scales and these items support the criterion-related validity of the questionnaire, this data should be interpreted with caution. Single item attitude scales may be less reliable than multi-item scales as they may be influenced by context, order of items or mood of the respondent (Abraham and Hampson, 1995). For example, the consistency in responses observed above may be partially attributed to the respondent's ability to understand that certain constructs logically belong together and a subsequent desire to appear consistent in their responses (Budd, 1987). In an attempt to diminish the influence of "ordering effects" items were not presented in "conceptual" order . For example, items expressing a particular view were, not grouped together. In order to diminish any effects of perceived "social desirability" of certain responses, questionnaire items were presented in a context which sanctioned the respondents "personal views" and assured the anonymity and confidentiality of responses, as described in Study 1.

The evaluation of the validity of the BMQ was also limited by the absence of data testing the predictive validity of the measure. This is currently being evaluated by examining inter-relations between BMQ scales and the items described above separated over a 3-month period.

Instability of the General-Harm sub-scale

The internal reliability of the General-Harm sub-scale was disappointing in three data sets (asthma, cardiac and general medical). Examination of individual item alphas showed that this could not be attributed to a single "rogue item" but was a true reflection of low

internal consistency of all items. However in other data sets this scale had a fairly high degree of internal consistency. The reason for this apparent disparity is unclear but seems to support the premise that representations of medicines in general may be complex and diffuse, and not easily grouped into coherent structures. People may have different views about particular types of medication so that it becomes difficult to identify consistent core representations about the nature of medicines as a whole. It may also indicate that patients with certain illnesses tend to develop a clearer representation of medication in general, which is perhaps influenced by their personal experience with prescribed medication.

The conclusion from this study is that, despite the clear limitations of the data described above, they provide preliminary evidence for criterion-related and discriminant validity and reliability of the BMQ and support its cautious use as a research tool within the context of the studies described in this thesis.

7.3 The distribution of medication beliefs among patients with chronic illnesses

This study comprises a series of analyses addressing the following research question: How are the main specific and general medication beliefs distributed within and across illness groups?

Previous studies described in this Chapter used PCA to identify core themes or factors underlying a selection of commonly-held beliefs about specific and general medication and the psychometric evaluation of these factors as scales comprising the BMQ. These studies provide preliminary evidence that the BMQ scales represent the 'main beliefs' which the sample of chronically ill patients held about prescribed and general medication. Scores on the BMQ scales could now be used to identify the proportion of people holding these beliefs and how strongly are they held

7.3.1 Method

Participants

- The 6 chronic illness groups comprising the main sample described in Section 6.3.

Measures

- The Beliefs about Medicines Questionnaire (BMQ), described in Section 7.2, using both the BMQ-Specific and BMQ-General scales

Procedure:

A series of analyses were conducted on the pooled cross-sectional data from the six illness groups comprising the main sample This was the data set from which the BMQ had been derived and evaluated.

Statistical techniques

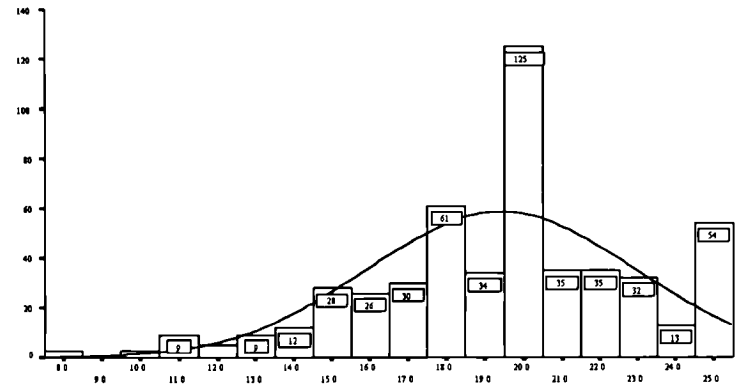
- The distribution of scores on the BMQ Specific and General scales was examined by frequency histogram.
- Cross-tabulation of BMQ-scale scores, dichotomised around the mid-point, was used to evaluate the degree of overlap between the dimensions of medication beliefs, represented by the BMQ factors.
- Spearman correlations (rho) were used to assess interrelations between the BMQ Specific and General factors.

7.3.2 Results

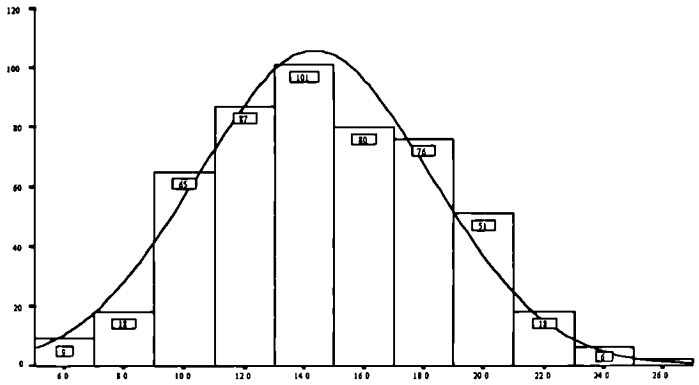
Frequency distribution of scores on BMQ scales

The distribution of scores on the four BMQ scales are shown In Figure 7.1. An interesting pattern emerged. Whereas beliefs about *General-Overuse*, *General-Harm* and *Specific-Concerns* were normally distributed, *Specific-Necessity* scores were heavily skewed towards the positive. As can be seen from Table 7.14, over 86.5% of the total sample of 524 patients, had higher than mid-point scores on the *Specific-Necessity* scale, indicating overall agreement with the view that their prescribed medicines were necessary for health. These percentages are much higher than those obtained for the *Specific-Concerns* (37.1%), *General-Harm* (16.1%), and *General-Overuse* (43.8%) scales.

BMQ-Specific Scales

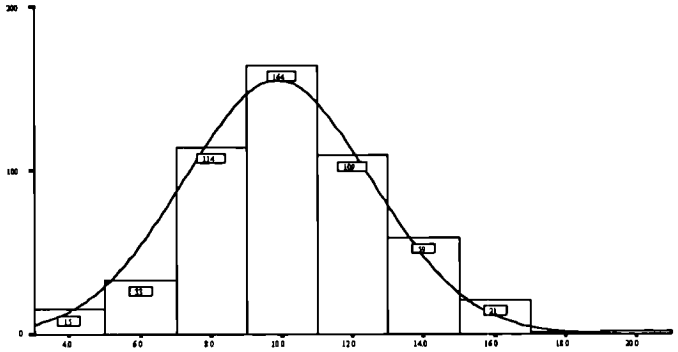


Specific Necessity Scores

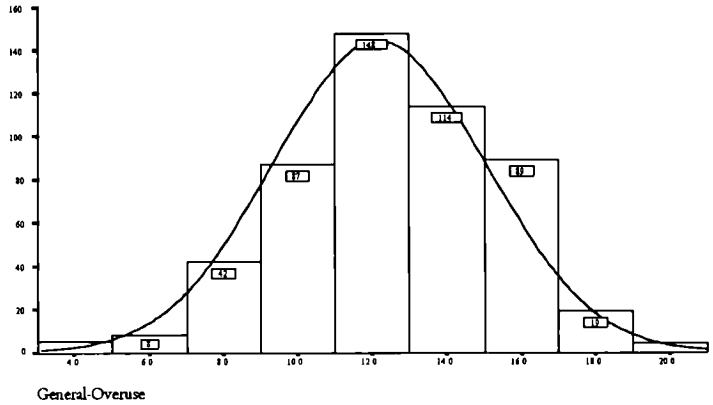


Specific Concerns Scores

BMQ-General Scales



General-Harm Scores



General-Overuse

Figure7.1 Frequency Distribution of scores on BMQ-Specific and General scales among the main sample (n=524)

Table 7.14 Scores on BMQ scales assessing beliefs about specific and general medication for six illness groups comprising the main sample (n=524)

Variable	Mean	SD	Percentage of subjects attaining scores above scale mid-point
Specific-Necessity	19.4	3.5	86.5
Specific-Concerns	14.3	3.9	37.2
General-Harm	9.9	2.7	16.1
General-Overuse	12.1	2.9	43.8

Relations between Specific and General medication beliefs

Spearman correlation coefficients between BMQ-General and BMQ-Specific scales are shown in Table 7.15. The degree of overlap within the Specific and General scales was examined by cross-tabulation of scale scores dichotomised at the scale mid-point. Table 7.16 shows a third of patients with strong beliefs in the necessity of their medication also harboured strong concerns about it. Considering beliefs about medicines in general, Table 7.17 shows that half the sample had lower than mid-point scores on both the *General-Overuse* and *General-Harm* scales indicating a generally benign view of medication and10% had a very negative view of medication with strong beliefs that medicines in general are essentially harmful and overused by doctors.

Table 7.15 Spearman correlation between BMQ scales (n=519)

	Specific-Necessity	Specific-Concerns	General-Harm
Specific-Concerns	-0.01		
General-Harm	-0.05	0.31*	
General-Overuse	-0.17	0.24*	0.40*

Note: *P<0.001

Table 7.16 Cross-tabulation of BMQ-Specific scales dichotomised at scale mid-point

			Specific-Concerns		
			1 = < scale mid-point	2 => scale mid-point	Total
Specific-Necessity	1 = Scores < scale mid-point	Count	48	21	69
		% within Specific-Necessity	69.6%	30.4%	100.0%
		% within Specific-Concerns	14 9%	11.0%	13.5%
		% of Total	9.4%	4.1%	13.5%
	2 = Scores > scale mid-point	Count	274	170	444
		% within Specific-Necessity	61.7%	38.3%	100.0%
		% within Specific-Concerns	85.1%	89.0%	86.5%
		% of Total	53.4%	33.1%	86.5%
Total		Count	322	191	513
		% within Specific-Necessity	62.8%	37.2%	100.0%
		% within Specific-Concerns	100.0%	100.0%	100.0%
		% of Total	62.8%	37.2%	100.0%

Table 7.17 Cross-tabulation of BMQ-General scales dichotomised at scale mid-point

			General-Harm		
			1 = < scale mid-point	2= > scale mid-point	Total
General-Overuse	= < scale mid-point	Count	261	29	290
		% within General-Overuse	90.0%	10.0%	100.0%
		% within General-Harm	60.3%	34.9%	56.2%
		% of Total	50.6%	5.6%	56.2%
	2 = > scale mid-point	Count	172	54	226
		% within General-Overuse	76.1%	23.9%	100.0%
		% within General-Harm	39.7%	65.1%	43.8%
		% of Total	33.3%	10.5%	43.8%
Total		Count	433	83	516
		% within General-Overuse	83.9%	16.1%	100.0%
		% within General-Harm	100.0%	100.0%	100.0%
		% of Total	83.9%	16.1%	100.0%

7.3.3 Discussion

The frequency distribution of BMQ factor scores provides an interesting insight into the way patients were thinking about medication. To begin with it is perhaps unsurprising that the great majority of this sample of chronically ill patients had strong beliefs in the necessity of their prescribed medication. However, approximately a third had clear concerns about their prescribed medication based on beliefs about dependence, long-term effects and the disruptive aspects of taking medication. Furthermore cross-tabulation showed a considerable overlap between necessity beliefs and concerns, in that 33% of those with strong beliefs in the necessity of their prescribed medication also harboured strong concerns.

Several things are striking about these findings. The first is that those patients with high concerns, probably had quite a different representation of their medicines than the doctors who had prescribed them. In the "medical view" none of the medicines which the patients were receiving would be considered to cause dependence or addiction, and few would be expected to cause serious long term adverse effects. Secondly, it is particularly salient that concerns did not influence patients' perceptions of the necessity of their medication (89% of patients with strong concerns believed that their medication was necessary). Rather, a third of the sample seemed to hold a complex representation of medicine in which firm beliefs about the *necessity* of medication were set against *concerns* about safety and the disruptive effects of taking medication. These patients had a "dualistic" view of their prescribed medication in which the potential for benefit is balanced by the potential for harm. This provides systematic evidence that this representation, which was first identified in small scale qualitative studies, conducted in individual diagnostic groups (Donovan and Blake, 1992; Fallsberg, 1991; Morgan and Watkins, 1988; Conrad, 1985), seems to be prevalent among chronically ill patients from a range of diagnostic groups.

Considering representations of medicines in general. Only 16% of the sample had strong beliefs that medicines were generally harmful, addictive poisons which should not be taken for long periods for time (*General-Harm*). However, this represents a significant minority when one considers that the sample comprised chronically ill patients, whose treatment hinged around prescribed medication. In this context, the fact that almost half the sample believed that medicines in general were overused by doctors *(General-Overuse),* is quite startling, and raises the question of what lies behind this view and why so many people hold it. This question could be addressed in a future research study using in-depth

interviews. One hypothesis is that people see the prescription of a medicine as a substitute for a patient-centred approach to care (Weinfield et al. 1996; Weinfield, 1992).

The correlations between BMQ scales, appeared to be the result of a logical 'common-sense' interpretation on the patients' part. For example, patients who believed beliefs that medicines in general are harmful, addictive poisons (*General-Harm*) which are overused by doctors (*General-Overuse*) were more likely to be concerned about medication prescribed for them. The very low correlation between beliefs about the necessity of prescribed medication (*Specific-Necessity*) and other scales shows that concerns about the harmful potential of specific prescribed medication and medicines in general are largely independent of the perceived need for medication.

The finding that specific and general beliefs are correlated in a logically consistent way does not answer the question of the direction of influence. For example beliefs about medication prescribed for personal use might arise directly from more general beliefs about medicines as a whole. Alternatively, beliefs arising from experience with specific medication (personal or that of significant others) might be extrapolated to medicines in general. It is however clear from this exploratory analysis of the relationship between beliefs, that although general beliefs are significantly correlated with specific beliefs the proportion of variance explained by the interaction is relatively small. This suggests that medication representations are influenced by a complex set of determinants and this will be investigated in more detail in Chapter 9.

In summary, these findings show a wide distribution of medication beliefs among chronically ill patients indicating a large degree of inter-individual variation in beliefs about specific and general medication. One of the questions arising from these data concerns the similarities and differences in the distribution of beliefs about medicines in general among well and ill populations. At a practical level, it is very clear that health care providers should not assume that medication means the same thing to all patients. Many patients were sceptical of the way in which medication is used by doctors. Furthermore, the need to take medication was a clear cause of concern for almost of third of the participants in this study. The determinants and effects of these concerns will now be addressed in more detail.

CHAPTER 8

The effects of medication beliefs in chronic illness

The studies described in Chapter 7 quantified some of the main beliefs that chronically ill patients hold about their prescribed medication and medicines in general. The current chapter will now address the question of how these beliefs relate to treatment adherence. It will describe a series of three studies addressing the following specific research questions:

1. What is the relationship between patients' main beliefs about prescribed and general medication and their reported adherence to medication prescribed for their illness?
2. To what extent are relations between medication beliefs and adherence specific to medication adherence?
3. What is the relative influence of illness cognitions and medication beliefs on reported active (adjusting the dose) and passive (forgetting doses) nonadherence to medication?

8.1 Investigating relations between medication beliefs and medication adherence

This study set out to address question 1 above by conducting two sets of analyses. First, the relationship between medication beliefs and adherence was investigated by examining correlations between BMQ factors and reported adherence to medication in several illness groups (Analysis A). This was followed by a second analysis in which the relative contribution of medication beliefs and demographic factors (age, gender, educational experience) to variance in reported adherence was examined using a series of multiple linear regression analyses (Analysis B).

The hypotheses were that:

1. The BMQ scales assessing negative views about medication (*Specific-Concerns*, *General-Overuse* and *General-Harm)* would be associated with lower reported adherence.
2. Higher scores on the *Specific-Necessity* scale would be associated with higher reported adherence.

3. The BMQ-Specific scales, which measure beliefs about prescribed medication would be more strongly correlated with reported adherence than the BMQ-General scales which assess more general beliefs about medicines as a whole.

8.1.1 Method

Participants

- The 6 chronic illness groups comprising the main sample described in Section 6.3.

Measures

- The Beliefs about Medicines Questionnaire (BMQ), described in Section 7.2.1.
- The Reported Adherence to Medication (RAM) scale, described in Section 6.4.4.
- The Reported Adherence to Insulin (RAI) scale, described in Section 6.4.4.1.
- Demographic characteristics of the patient: age, gender and educational experience, assessed using the method described in Section 6.4.8.

Procedure:

This study utilised the data set obtained from the six illness groups comprising the main sample. This was the data set from which the BMQ had been derived and evaluated.
For the purposes of this study, insulin-treated diabetics (n=64) and tablet-treated diabetics (n=35) were considered separately. This was necessary to reflect differences in the type of adherence instructions. For patients receiving oral hypoglycaemic agents (tablet-treated), a tendency to adjust or alter the dosage of medication is considered to be non-adherent. In contrast, the insulin-treated diabetics were required to take an active role in adjusting the dose of their insulin in response to dietary intake and blood/urine glucose measurements. Thus for these patients, a tendency to adjust the dose of their insulin indicates adherence to the treatment instructions. This essential difference was taken into account in the adherence measures used as detailed in Section 6.4.4.1.

Statistical techniques

- Correlations between BMQ and RAM/RAI scales were investigated using Spearman correlation coefficient (rho).
- The percentage variance in reported adherence explained by medication beliefs and demographic variables was investigated by multiple linear regression using the stepwise entry and removal method, setting probability F for entry and removal at 0.05 and 0.01.

The rational for using this parametric technique with ordinal data (eg gender and the BMQ, RAM/RAI scales) is presented in Section 6.6.

8.1.2 Results

Analysis A: Medication beliefs as correlates of medication adherence

The mean scores on the adherence self report scales are shown in Table 8.1. Spearman correlations between BMQ scales and self-reported adherence are shown in Table 8.2.

Table 8.1 Mean scores on the reported adherence to medication (RAM/RAI) scales and Cronbach alpha values as a measure of internal consistency

Sample	n	Mean	SD	Variance	Cronbach's alpha
Asthma clinic	78	10.47	3.20	10.25	0.60
Psychiatric clinic	89	10.09	3.49	12.20	0.73
General-medical IP	90	9.30	3.18	10.12	0.67
Cardiac IP	116	8.72	2.81	7.92	0.67
Dialysis IP	47	8.04	3.67	13.43	0.83
Diabetes: Insulin treated*	64	11.68	3.97	15.77	0.73
Diabetes Tablet treated	35	7.91	2.30	5.27	0.50

* 2-item scale

Table 8.2 Spearman correlation between self-reported adherence to medication and BMQ factors

	Asthma	Diabetes Insulin-treated	Diabetes Tablet-treated	Renal	Cardiac	Psychiatric	General Medical Inpatients
Specific-Necessity	-.23*	-.39**	-.33*	-.02	-.20*	-.03	-.22*
Specific-Concerns	.23*	.28*	.49**	.39**	.19*	-0.1	.37**
General-Harm	.09	.17	.36*	.25	.16	.08	.05
General-Overuse	.17	.08	.48**	.30*	.17	.11	.26*

p=<0.05; **p=<0.01

It can be seen from Table 8.2 that correlations between medication beliefs and reported medication adherence were fairly consistent across illness groups. With the exception of psychiatric out-patients, statistically significant correlations were obtained between BMQ-Specific variables and adherence in all illness groups. Correlations were in the predicted direction. Stronger beliefs in the necessity of prescribed medication *(Specific-Necessity)* were associated with higher reported adherence whilst concerns about the potential

adverse consequences of prescribed medication *(Specific-Concerns)* correlated with lower reported adherence.

In most of the illness groups, beliefs about medicines in general had a relatively small effect on adherence. Where significant correlations were noted between general beliefs and adherence these were in the predicted direction. For example, renal, general medical and tablet-treated diabetic patients with stronger beliefs that medicines in general are overused by doctors, as indicated by higher scores on the *General-Overuse* scale, reported lower medication adherence, as indicated by higher scores on the RAM scale. Similarly, tablet treated diabetics who believed that medicines in general are harmful addictive poisons which should not be taken for long periods of time also reported lower adherence.

Analysis B: Multiple linear regression

The purpose of analysis 2 was to assess the differential contribution of medication beliefs to variance in self-reported adherence. Data from the asthma, dialysis, cardiac and general medical inpatients samples were combined to form a larger sample. It was thought that this larger sample representing a variety of common chronic illnesses would provide a "global view" of how personal representations might influence reported adherence. The diabetic and psychiatric samples were omitted from the analysis. The diabetic group were omitted because 65% of the sample were treated with insulin and so completed a different adherence scale (RAI scale). Data on educational experience was not available for the diabetic sample and so the tablet-treated patients, who completed the RAM scale, were also omitted from the combined data set. The psychiatric sample were omitted because no significant correlations between beliefs and adherence were found in this data set.

Stepwise entry and removal of Specific and General medication beliefs and demographic variables (age, gender and educational experience) resulted in a simple model in which beliefs about prescribed medication (Specific) and age accounted for 27% of the variation in reported adherence. The results, shown in Table 8.3, indicate that reported adherence was strongly related to patient age and beliefs about medicines. Age alone accounted for 14% of the variance in reported adherence with younger patients reporting lower adherence. Specific medication beliefs added a further 13% to the explained variance. Beliefs about specific medication prescribed for personal use had a much stronger influence on reported adherence to those medicines than did global beliefs about medicines in general, confirming hypothesis 3. Patients with stronger *Specific-Concerns* about the potential adverse effects of their own medication tended to report lower

adherence. Similarly those with stronger beliefs about the necessity of their medication reported that they were less likely to depart from the treatment instructions confirming hypothesis 2.

Table 8.3 Linear regression model for self reported adherence [combined data from the asthma, renal dialysis, cardiac and general medical in-patients (n=336)]

Variable	B	SE B	Beta	T	Sig T	Cumulative R Square
Age	-.06	.01	-.32	-6.47	<.01	.14
Specific-Concerns	.26	.04	.32	6.53	<.01	.23
Specific Necessity	-.19	.05	-.20	-4.09	<.01	.27

8.1.3 Discussion

Specific and General medication beliefs as correlates of adherence

The correlations between Specific and General medication beliefs and reported adherence to treatment were logically consistent. In most of the illness samples, strong beliefs in the necessity of prescribed medication for maintaining health (higher scores on the *Specific-Necessity* scale) seemed to stimulate adherence and stronger concerns about the potential adverse effects of prescribed medication (higher scores on the *Specific-Concerns* scale) were associated with lower reported adherence. Although the magnitude of the correlations varied, the pattern of correlations between BMQ-Specific scores and reported adherence was fairly consistent across a range of chronic illnesses and associated treatments.

Correlations between reported adherence and BMQ-General scales were less consistently significant but were in the predicted direction. Views about medicines in general had a more direct influence on reported adherence in some illness groups than others. General beliefs were less influential for asthma, cardiac and insulin treated diabetic patients than for renal, general medical , psychiatric and tablet treated diabetic patients. A possible explanation for this is that the differential importance of general beliefs might be a function of the "perceived salience" of the specific medication commonly prescribed for the condition. For example, it may be that a negative orientation towards medicines, stemming from beliefs that medicines in general are harmful addictive poisons which are overused by

doctors, might be less influential if the patient perceives a clear link between their prescribed medication and benefit or potential harm. This explanation is supported by the finding that general beliefs were less influential in asthma, cardiac and insulin treated diabetic samples where there is often a clear link between medication taking and symptomatic benefit. Conversely, patients receiving oral treatment for diabetes, and renal patients whose medication is secondary to "life-saving" haemodialysis sessions, are perhaps likely to perceive a weaker link between prescribed medication and tangible benefit. For these patients, the specific prescribed medication may be less salient so that views about medicines as a whole become more prominent in adherence decisions. This explanation is clearly tentative and further work is needed to test its validity. This may be best achieved by prospective longitudinal studies, involving newly diagnosed patients with a range of chronic illnesses. The differential effects of general and specific beliefs on adherence could then be studied at various stages. Moreover, it would be possible to investigate patients' views about their prescribed medication before and after they had observed its effects on their condition.

Concerns and Necessity beliefs, as predictors of adherence

Regression analysis in the combined data set gave an indication of the broader contribution of medication beliefs to adherence behaviour in the self-management of chronic illness. The key finding here was that patients' beliefs about medication were predictive of reported adherence, suggesting that many patients were making active decisions about adherence, based on their own beliefs, rather than simply complying with treatment advice. In particular, patients with stronger concerns about their medication reported lower adherence. The relative influence of *Specific-Concerns* and *Specific-Necessity* beliefs on reported adherence is interesting. In this sample of chronically patients, medication adherence was much more strongly influenced by concerns about the potential of prescribed medication to result in long term adverse effects, dependence and disruption than by beliefs in its necessity. It is salient that, although the majority of patients believed that their prescribed medication was necessary for maintaining health, approximately a third had strong concerns about their medication and these patients were less adherent. Thus, the interplay between concerns and necessity beliefs implies a risk-benefit analysis and subsequent attempts to moderate the perceived potential for harm by taking less.

The relative contribution of concerns and necessity beliefs may vary in different clinical situations. In the present sample of chronically ill patients, those with stronger *Specific-Necessity* beliefs were more adherent. However, the variance explained was small with

Specific-Necessity scores adding 4% to the total variance in adherence explained by the other variables within the model. The relatively small correlations between *Specific-Necessity* beliefs and adherence may be a function of the low degree of spread within this data. As discussed in Section 7.5, over 85% of the sample had higher than mid-point scores on this scale. Further studies are now needed to determine whether *Specific-Necessity* beliefs show greater variation and have a stronger influence on adherence when medication is prescribed for short term use or when the patient perceives the illness to be of short duration.

Lack of interaction between beliefs and adherence in the psychiatric clinic sample

The lack of significant interactions between medication beliefs and adherence within the psychiatric clinic sample was inconsistent with the above findings. Possible explanations for this apparent anomaly are that other cognitions such as perceived vulnerability to relapse or normative beliefs may be more influential than *Specific-Concerns* or *Specific-Necessity* beliefs (Hogan et al. 1983; Budd et al. 1996; Cochran and Gitlin, 1988). In addition the type of medication concerns which are addressed by the *Specific-Concerns* dimension may be less salient for this group who may be more concerned about the present experience of side-effects than future worries about dependence or long-term effects. These issues are discussed in more detail in Chapter 10.

The effect of age on adherence

The observed relationship between age and adherence reported here is consistent with more recent work showing that it is mistaken to regard older patients as a homogenous group of low adherers (Lorenc and Branthwaite, 1993). Further work is needed to explain why younger patients reported lower adherence. This may be an artefact attributable to a greater willingness to report non-adherence. However, the context of adherence questions was controlled to encourage truthful reporting. This finding adds to the growing body of research linking lower adherence with younger age (Daniels et al. 1994; Sherbourne et al. 1992; DiMatteo et al. 1993; Frazier et al. 1994; Lorenc and Branthwaite, 1993). The explanation for this effect may lie in cognitive differences in the approach to illness associated with older age. Older people tend to adopt a more cautious approach to the maintenance of health (Leventhal et al. 1993a; Cameron et al. 1993; Leventhal et al. 1993b). Consequently, once the patient has accepted the advised behaviours as necessary and valid, they tend to adhere to them more carefully and systematically (Leventhal and Crouch, 1997). These issues were discussed in more detail in Chapter 10.

Limitations of the study Several methodological limitations mean that these findings should be interpreted with caution. The first concerns the method of assessing adherence behaviour. In common with most "measures" of adherence, self-report does not detail the exact number of medications taken. Moreover, the accuracy of self-report has been questioned on the grounds that patients may be reluctant to admit to non-adherence and that generally tends to over-estimate adherence by about 20% (Caron, 1985). However, others have suggested that self-report is a useful method for grading patients according to their "relative standing on the adherence dimension" (Ley and Llewellyn, 1995; Haynes et al. 1980). In this study adherence questions were phrased in a non-threatening way so as to diminish self-presentational bias and located in two different places within the questionnaire to limit ordering effects. A further attempt to improve the validity of patients' self-report was the use of continuous scales rather than simple dichotomous variables and checking that the internal reliability and test-retest reliability of the scales was adequate. However, the RAM scale has not been fully validated against other measures of adherence behaviour. Until this is achieved, the results of this study should be interpreted with caution and any conclusions reached about the effects of medication beliefs on adherence are preliminary. The cross-sectional design of this study represents a further limitation in that one cannot be sure about direction of influence between beliefs and reported behaviour. Thus, the predictive effect of medication beliefs on medication behaviour should now be examined using a longitudinal study design.

In summary, significant correlations were observed between medication beliefs and reported adherence across a range of chronic illness groups. Although, the limitations of the methodology used suggest the need for a cautionary approach when generalising from these findings, they lend tentative support for the notion that patients' representation of medication influence adherence decisions.

8.2 Examining the differential relationship between medication beliefs and adherence to medication and fluid/dietary restrictions in a sample of hospital haemodialysis recipients

The analyses described in the previous section showed that patients' beliefs about their prescribed medication accounted for a significant amount of variance in their reported adherence to medication. The present study set out to examine the degree to which these relations were specific to medication adherence. Before concluding that beliefs about medication directly influence medication adherence it was necessary to exclude the possibility that scores on the BMQ-Specific dimensions are merely "surrogate markers" for other factors. In particular, it was necessary to question the degree to which the Specific-Concerns dimension is measuring cognitive and emotional representations of prescribed medication rather than negative attitudes to the illness and treatment as a whole. One way of addressing this question is to investigate whether BMQ factor scores are also associated with adherence to other aspects of the treatment regimen such as dietary control. If the scale was addressing medication beliefs rather than general attitudes to treatment then the BMQ-Specific factor scores would be more strongly associated with adherence to medication than adherence to other aspects of treatment.

The renal sample described in Section 6.3.1.3, comprising patients receiving hospital haemodialysis as a treatment for End Stage Renal Disease (ESRD), provided an opportunity to study the effects of medication beliefs on separate treatment modalities. ESRD is a chronic illness which necessitates continuous medical treatment. Patients receiving haemodialysis are required to adhere to a tripartite regimen of attendance at hospital dialysis sessions, fluid and dietary restrictions and a complex medication schedule (Will and Johnson, 1994). Although haemodialysis sessions are time-consuming and unpleasant, serial non-attendance is relatively rare as missing only a few consecutive sessions may endanger life. However, non-adherence to medication and fluid/diet restrictions is viewed as a major issue (Lowry and Atchison, 1980). Thus the renal sample could be used to test the study hypotheses that:

1. Beliefs about medication would be significantly related to reported adherence to medication, but not to adherence to fluid/diet restrictions.
2. Views about fluid/diet restrictions would be significantly related to adherence to fluid/diet restrictions but not to reported medication adherence.

8.2.1 Method

Participants

- The renal sample comprising recipients of hospital haemodialysis, described in Section 6.3.1.3.

Measures

- Beliefs about treatment
    1. Beliefs about specific and general medication were assessed using the The Beliefs about Medicines Questionnaire (BMQ), described in Section 7.2.1.
    2. Views about the fluid and dietary restrictions were assessed by a single item: '*My fluid and dietary restrictions are too strict*'.
       Responses were scored on a 5-point Likert scale where 1 = strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree. Thus higher scores indicate stronger beliefs that fluid/diet restrictions are too strict.
- Adherence Indicators
    3. Reported adherence to medication was assessed using the RAM scale, described in Section 6.4.4
    4. Adherence to fluid/diet restrictions was assessed using the clinical assessment procedure employed by physicians on the renal unit. An inter-dialysis weight gain of greater than 2Kg is indicative of low adherence to fluid/diet restrictions. Records of inter-dialysis weight changes over a three month period immediately prior to completion of the study questionnaire were retrospectively collected from the medical notes. Patients were then assigned a fluid/diet adherence score from 1 to 5 according to the percentage of results found to lie outside the clinically acceptable range of less than 2Kg gain between dialysis sessions, shown in Table 8.5 in the results section.
- Demographic characteristics of the patient: age, gender and educational experience, assessed as described in Section 6.4.8.

Statistical techniques

Relationships between beliefs, sociodemographic data, self-reported medication adherence, and fluid/diet adherence were quantified using the Spearman correlation coefficient for ordinal data and by multiple linear regression.

Procedure:

This was an analysis of cross-sectional and retrospective data collected from the renal sample (n=47) This data set also contributed to the development and evaluation of the BMQ as described in Chapter 7.

8.2.2 Results

Beliefs about treatment

Computed mean scores for BMQ Specific and General scales are shown in Table 8.4, together with the percentage of the sample attaining scores above the scale mid-point. The latter can be said to have stronger beliefs in the concept represented by the scale.

Table 8.4 Scores on BMQ scales assessing beliefs about specific and general medication for the Renal sample (n=47)

Variable	Mean	SD	Percentage of subjects attaining scores above scale mid-point
Specific-Necessity	19.5	2.8	89.4
Specific-Concerns	13.8	4.3	31.9
General-Harm	9.9	3.8	19.1
General-Overuse	12.7	3.2	57.4

It can be seen from Table 8.4 that the distribution of specific and general medication beliefs were almost identical to those observed in the combined sample of six illness groups, described in section 7.2. Almost 90% believed in the necessity of medication prescribed for their renal condition, as indicated by higher than mid-point scores on the *Specific-Necessity* scale. However, 32% of the sample also exhibited strong concerns. Concerns about renal medication were not associated with lack of belief in its necessity, since all patients with higher than mid-point scores on the *Specific-Concerns* scale also had higher *Specific-Necessity* scores. Thus, a third of the sample had an ambivalent attitude to their medication in which firm beliefs about necessity were tempered by more negative attitudes arising from concerns about long-term safety, dependence and the perceived disruptive effects of the medication regimen. Although *Specific-Necessity* belief scores were skewed towards the positive, concerns about prescribed medication and beliefs about medicines in general were normally distributed. Many patients had a fairly negative view of medicines in general with 57.4% of the sample believing that these are overused by doctors and 19.1% that these are harmful addictive poisons which should not be taken for long periods of time.

Concerns about medicines prescribed for ESRD correlated with beliefs that medicines in general are harmful, addictive poisons (rho=0.45; p<0.01) which are overused by doctors (rho=0.6; p<0.001). Most patients (91%) with strong concerns about renal medication believed that medicines in general are over used by doctors and in 40% of cases this was associated with a belief that medicines in general are harmful, addictive substances. Twenty patients (43%) felt that their fluid/diet restrictions were too strict. Demographic variables had little influence on beliefs about treatment except that younger patients were more likely to believe that their fluid/diet restrictions were too strict (rho=0.39; p=0.007).

Adherence to treatment

Self-reported adherence to medication

The frequency distribution of scores on the medication adherence self-report scale are shown in Figure 7.1.

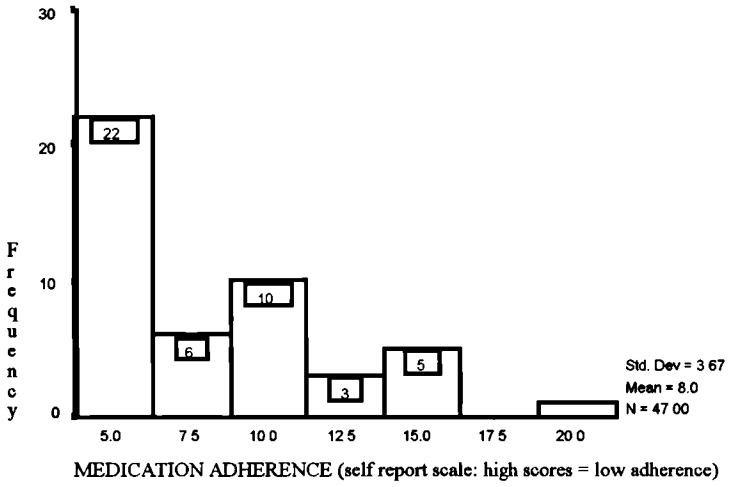


Figure 7.1 Frequency distribution of scores for the medication adherence self-report scale

Adherence to fluid/diet restrictions

The percentage of inter-dialysis weight gain measures outside the clinically acceptable range is shown in Table 8.5.

Table 8.5 Adherence to fluid/diet restrictions

Weight changes over 2Kg as a percentage	Fluid/diet Adherence Score	Frequency	Percentage
none >2Kg	Score =1	7	14.9
1%-33% > 2Kg	Score =2	17	36.2
34%-66% >2Kg	Score =3	12	25.5
67-99% >2Kg	Score =4	10	21.3
100% >2Kg	Score =5	1	2.1
Total		47	100.0

Relationships between patients' beliefs and treatment adherence

Patients' beliefs about their treatment were related to medication and fluid/diet adherence in a coherent way. Concerns about renal correlated with lower medication adherence (rho=0.39; p=0.008). Patients who believed that their fluid/diet restrictions were too strict were less likely to adhere to them as indicated by the frequency of inter-dialysis weight gain greater than 2Kg (rho=0.54; p<0.01). Younger patients were less adherent to fluid/diet restrictions (rho=0.29; p<0.05) and reported lower medication adherence (rho=0.36; p<0.05). Medication and fluid/diet adherence were not significantly correlated. Spearman correlations between beliefs and adherence to medication and fluid/diet restrictions shown in Table 8.6, indicate that, although specific beliefs about medicines influenced adherence to medication and specific beliefs about fluid/diet restrictions influenced adherence to them, these two areas of beliefs and behaviour were unrelated.

To investigate the differential contribution of beliefs about medicines and fluid/diet restriction and demographic variables to variance in adherence behaviours, separate linear regression analyses were performed using each type of adherence as the dependent variable. In each analysis, the contribution of treatment beliefs, demographic variables (age, gender, educational experience) and clinical factors (duration of dialysis and number of prescribed medications), was tested by stepwise entry and removal. The linear regression models, shown in Table 8.7, provide further evidence that beliefs about specific treatments had a selective effect on adherence to those treatments. Patients' beliefs about treatment were more closely associated with adherence than other variables such as duration of illness, number of medications prescribed, or basic sociodemographic data such as age, gender and educational experience. An exception was that younger patients reported lower medication adherence independently of medication beliefs. The only variable predicting adherence to fluid/diet restrictions was patients' personal beliefs about the restrictions.

Table 8.6 Spearman correlations between beliefs about treatment and adherence (renal sample n=47)

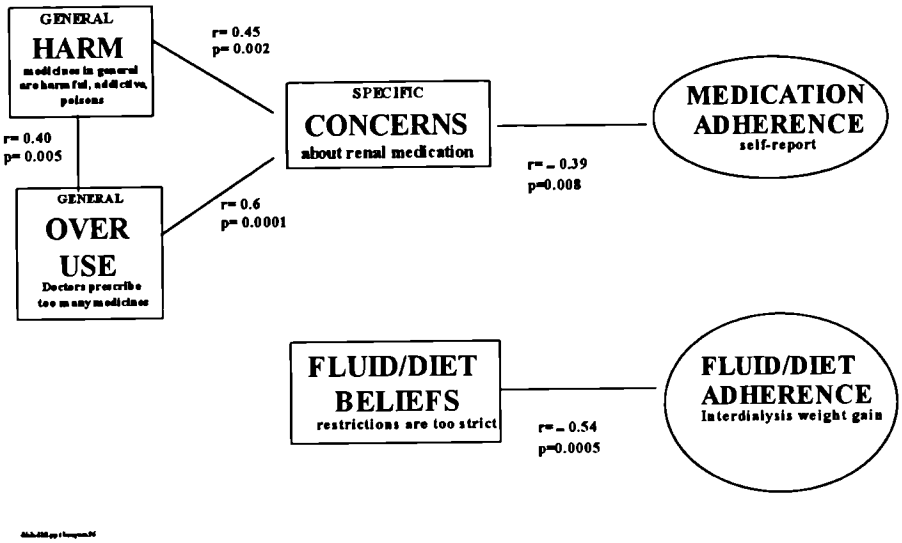
BELIEFS ABOUT TREATMENT	Self-Report of Adherence to Medication	Inter-dialysis Weight Gain
Concerns about long-term effects and potential for dependency of renal medication (Specific-Concerns)	rho = 0.39 p = 0.008	rho = 0.02 p = 0.89
Beliefs that fluid and dietary restrictions are too strict	rho = 0.04 p = 0.8	rho= 0.55 p < 0.001

Table 8.7 Linear regression models for adherence to treatment (renal sample n=47)

Self-reported adherence to medication as dependent variable						
Variable	B	SE B	Beta	T	Sig T	R Square
Concerns about renal medication (Specific-Concerns)	.32	.11	.37	2.86	.01	17
Age	-.07	.03	-.32	-2.50	.02	10
Adherence to fluid/diet restrictions as dependent variable						
Variable						
Beliefs that fluid/diet restrictions are too strict	.46	.11	.55	4.37	.0001	30

8.2.3 Discussion

The discussion of the above findings is structured around the assumption that beliefs influence behaviours, in accordance with self-regulatory theory. However, since this was a cross-sectional study it is equally possible that some of these beliefs were shaped by the behaviour pattern (Gerrard et al. 1996). The pattern of relationships between beliefs and behaviours identified confirm the study hypotheses and are shown diagramatically in Figure 7.2.



Note r= Spearman's rho

Figure 8.2 Diagrammatic representation of correlations between beliefs and adherence behaviours

The fact that adherence to medication was not correlated with adherence to fluid/diet restrictions shows that patients may adhere to some aspects of their treatment but not others. The most important finding was that specific beliefs were related to specific reported adherence behaviours in a meaningful and discriminating way. For example, concerns about the long term effects and potential for dependence of prescribed medication were associated with lower rates of self-reported medication adherence but not with lower adherence to fluid and dietary restrictions. Similarly, patients who believed that their fluid and dietary restrictions were too strict were less likely to adhere to them. This finding confirmed the hypothesis that medication beliefs would have a specific effect on medication adherence and is consistent with the notion that nonadherence may result from a rational decision based on personal beliefs about individual aspects of the treatment. In particular, patients who thought that their medicines were harmful took less of them and those who believed that their fluid/diet restrictions were too strict exceeded the recommendations for fluid intake. The observation that younger patients reported lower medication adherence is consistent with findings reported in Section 8.1 of this chapter.

8. 3 The selective influence of medication and illness beliefs on active and passive non-adherence to medication

Section 8.1 and 8.2 showed that medication beliefs were selectively related to reported medication adherence. These findings imply that patients' representations of treatment should be considered as components of self-regulatory theory. Theory and research in this area has focused on the role of representations of illness and has not specifically considered beliefs about treatment (Leventhal et al. 1992; Skelton and Croyle, 1991) . Thus, the studies reported in this chapter raise several questions. The first concerns the relative influence of illness and medication beliefs on medication adherence. A second question concerns the type of adherence behaviour which is affected by these beliefs. A distinction is sometimes drawn between two separate but related aspects of medication non-adherence. Non-adherence may be unintentional or *passive* if the patient's plan to take medication is thwarted by barriers such as forgetting, or the inability to follow treatment instructions because of poor understanding or physical problems such as poor eyesight or impaired manual dexterity. Alternatively, it may be the intentional result of a decision not to take the treatment as instructed. In this case the non-adherence is *active* (Weintraub, 1990; Cooper et al. 1982). The present study addresses these issues. The specific questions were:

1. What is the relative contribution of beliefs about medication, illness representations and beliefs about control over asthma to variance in passive and active nonadherence to asthma medication?
2. What is the relation between clinical and subjective indicators of appraisal on coping procedures (adherence) and representations?

The conceptualisation of beliefs, adherence (coping) and appraisal are detailed below and shown in Figure 8.3.

Medication beliefs These were conceptualised as the BMQ Specific and General factors described in Chapter 7. In common with the studies described earlier the concept of *Specific* medication beliefs refers to the patients' representations of their medication regimen (e.g. 'medicines prescribed for your heart condition') rather than their views about the individual components (e.g. 'aspirin prescribed for your heart condition'). Thus, *Specific* representations are the patients' composite view of their individual medicines. We know little about the extent to which this composite view is influenced by individual components of the regimen. In the asthma sample it was possible to explore this issue further since all but three patients were receiving coticosteroids (steroids) as part of their

medication regimen. Thus two aspects of Specific medication were included: patients' views about their prescribed medication regimen as a whole and their view about the steroid component of the regimen. The method of assessing beliefs about steroids is described later in Section 8.3.1

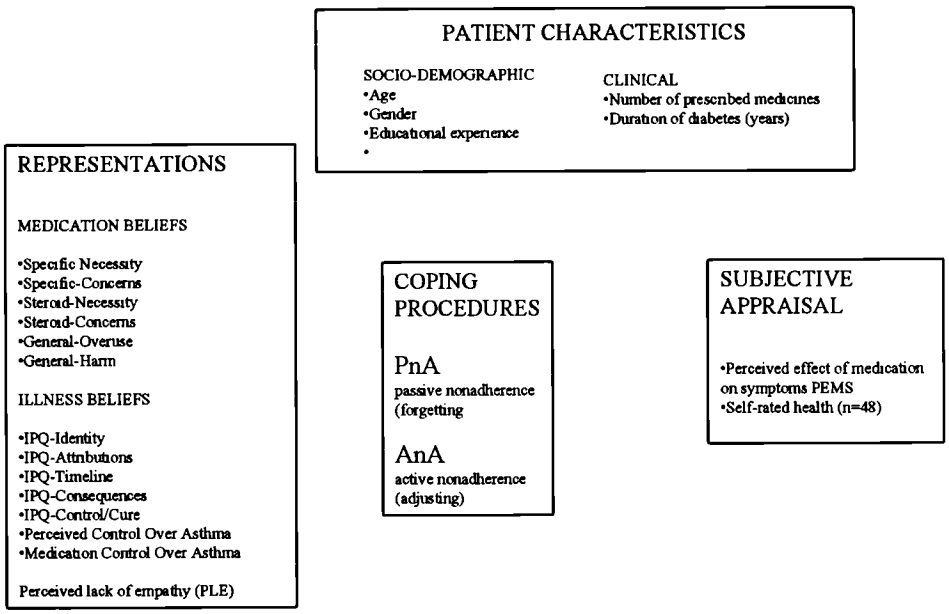


Figure 8.3 Variables included in asthma study

Illness beliefs Several illness related cognitions were included. First, the content of the 5 components of illness representation described by Leventhal and colleagues (1980) identity, cause, timeline, consequences and potential for cure/control. Patients' perceptions of the degree of empathy conferred by medical and nursing staff were also evaluated as this is thought to have an influence on adherence behaviours (Meichenbaum and Turk, 1987).

Control beliefs It has been suggested that those with high internal control beliefs would be more likely to engage in health promoting activities (Norman and Bennett, 1996). One might therefore expect high internals to be more adherent to medication. The degree of internality in relation to perceived control of asthma was assessed as was the extent to which patients attributed control over asthma to their medication.

Medication adherence Two aspects of medication adherence were distinguished. The tendency to forget to take medication (passive nonadherence: PnA) and the tendency to

deliberately alter the dose of medication outside the physicians recommendations (active nonadherence: AnA) were considered separately.

Appraisal Two indicators of subjective appraisal were included: self-reported health and perceived effects on symptoms.

Clinical measure of asthma severity Peak expiratory flow rate (PEFR).

8.3.1 Method

Participants

The asthma sample (n=78) detailed in Section 6.3.1.1.

Measures

- *The Illness Perception Questionnaire (IPQ)* (Weinman et al, 1996- see Section 6.4.1). Note: In this study both methods for assessing causal beliefs were used ie scoring responses to individual causal items and by summing the number of causal attributions made by the patient.

- *Beliefs about control over asthma*: were assessed using a modified version of a the Perceived Control Over Recovery scale (Partridge and Johnston, 1989) as described in Section 6.4.2. The extent to which control over asthma was attributed to medication was assessed on the basis of Likert scale responses to a single item statement: *"Whether my asthma gets better or worse depends on how well my medicines work"*, scored from 1 = strongly disagree to 5 = strongly agree as detailed in Section 6.4.2.

- *The Beliefs about Medicines Questionnaire (BMQ)*, described in section 7.2. *Specific-Necessity* and *Specific-Concerns* scales were used to assess patients' composite views about their asthma medications. *General-Harm* and *General-Overuse* scales were used to assess beliefs about medicines in general.

- *Beliefs about Steroid Scales*

  The asthma sample completed the 16 items assessing beliefs about medication prescribed for their asthma in addition 18 items assessing beliefs about medicines in general as described in Chapter 7 and shown in Table 7.1. In addition, patients receiving regular steroid treatment for their (n=75) were asked to complete a further 10 items assessing their views about steroid treatment in particular. Due to restrictions on the

number of items which could be administered to patients 10 items were selected to represent positive (n=5) and negative (n=5) views about steroids. The majority of these items were obtained by simply changing the phrasing of one of the 16 Specific items to reflect the steroid subject e.g. 'I sometimes worry about the long-term effects of my *steroids*'. Others were included because they would provide data which were of particular interest to the clinical staff e.g. *'I have been given enough information about my steroids'* and *'My steroids are the most important part of my treatment'* The scale items are shown in Appendix 11. The 10 items dealing with beliefs about steroid were entered into a Principal Components Analysis with non-orthogonal (OBLIMIN) rotation which resulted in two factors shown in Appendix 11. As these seemed to be analogous to the *Specific-Concerns* and *Specific-Necessity* factors of the BMQ they were labelled: Steroid-Concerns and Steroid-Necessity.

It should be noted that the Steroid-Concerns and Steroid-Necessity scales was exploratory and was not originally intended to be developed as evaluated in measures in the same way as the BMQ.

- *Perceived lack of empathy from medical and nursing staff (PLE)*: described in Section 6.4.3.

- *Reported adherence to medication:* was assessed using the RAM scale described in Section 6.4.4.2. However, the passive and active aspects of adherence elicited by this scale were considered separately as two 2-item constructs as described in Section 6.4.4.2.

- *Measures of subjective appraisal:* Patients' appraisal of the effect of their medication on symptoms was evaluated using responses to the single statement *"My medicines make me feel better"*, scored on a 5-point Likert scale where 1= strongly disagree and 5= strongly agree. A further more general appraisal assessment was the 7-item self-rated health scale adapted from the SF-36 measure (Jenkinson et al. 1994; Ware, Jr. and Sherbourne, 1992) described in Section 6.4.5.
- *Clinical outcome*: An indication of clinical outcome was provided by Peak Expiratory Flow Rate (PEFR, peak flow) measurements as a percentage of the expected value. This is the clinical measure of asthma severity routinely used by the clinic physicians. PEFR measurements were taken by the researcher before patient's completed the questionnaires. Patients were asked to perform three serial peak flows as is usual (Town et al. 1990). The highest value was then compared with the expected value for a

non-asthmatic patients of similar age, sex and weight obtained from standard tables. The result was expressed as a percentage of the expected value.

Procedure

Data collection was carried out as described in Section 6.5. The analysis of the data preceded in two stages. First an exploratory analysis of correlations between measures of adherence and other variables, to identify the statistically significant correlates of AnA and PnA. This was followed by multiple linear regression analyses to identify the proportion of variance in AnA and PnA explained by their significant correlates. The Self-rated Health measure was introduced half-way throughout the study and so was completed by only 48 patients.

Statistical techniques

- Correlations between beliefs about inhaled steroid medication and the beliefs about the asthma regimen as a whole were assessed by Spearman's correlation coefficent (rho)
- Correlations between RAM scales assessing PnA and AnA and measures of illness perceptions, medication beliefs, appraisal processes and PEFR values were investigated using Spearman's correlation coefficient (rho).
- The percentage variance in reported PnA and AnA explained by other study variables was investigated by multiple linear regression using the stepwise entry and removal method, setting probability F for entry an removal at 0.05 and 0.01. The rational for using this parametric technique with ordinal data is presented in Section 6.6.

8.3.2 Results

Scale and item mean scores for the variables used in this study are shown in Table 8.8. The frequency distributions of reported AnA and PnA are shown in Figures 8.4 and 8.5 respectively.

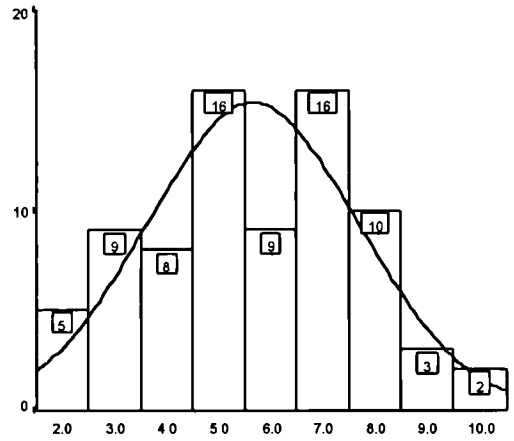


Figure 8.3 Frequency distribution of reported active nonadherence (AnA) (n=78, asthma clinic attenders)

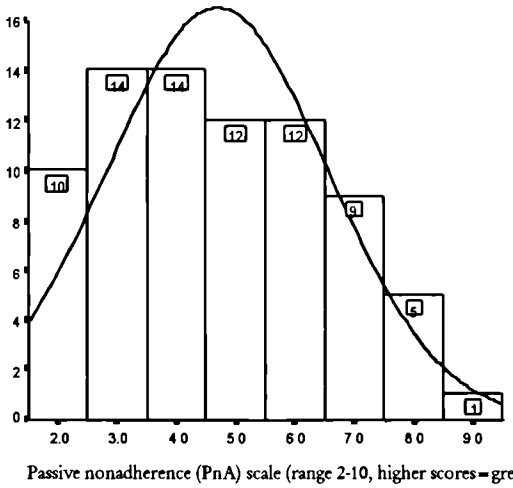


Figure 8.4 Frequency distribution of reported passive nonadherence(PnA) (n=78, asthma clinic attenders)

Interrelations between beliefs about inhaled steroid medication and beliefs about the asthma regimen as a whole are shown in Table 8.9. Correlations showed fairly strong associations between views about the steroid component and the regimen as a whole. Spearman correlations were also computed between representations, appraisal indicators, socio-demographic and clinical characteristics and the reported frequency of active and passive nonadherence are shown in Table 8.10.

Table 8.8 Scale responses and measures of internal consistency (Asthma sample n=78)

Variable	No. of items	Mean	STD	Cronbach alpha
MEDICATION REPRESENTATIONS				
Specific Necessity	5	3.9	0.6	0.80
Specific-Concerns	5	3.2	0.8	0.75
Steroid-Necessity	5	3.3	0.8	0.83
Steroid-Concerns	5	3.5	0.8	0.78
General-Overuse	4	2.9	0.6	0.74
General-Harm	4	2.0	0.6	0.47
ILLNESS COGNITIONS				
IPQ-Identity	16	2.1	0.44	0.84
IPQ-Timeline	2	3.8	0.8	0.78
IPQ-Consequences	8	3.1	0.4	0.70
IPQ-Attributions	1	2.2	1.3	Ψ
IPQ-Cure	1	2.5	1.1	
IPQ-Causal beliefs				
chance	1	2.7	1.3	Ψ
other people	1	2.6	1.1	Ψ
inherited	1	3.1	1.2	Ψ
stress	1	3.1	1.2	Ψ
diet	1	2.4	0.9	Ψ
pollution	1	3.5	1.1	Ψ
own behaviour	1	2.3	0.9	Ψ
germ or virus	1	2.6	1.1	Ψ
Perceived control over asthma	9	3.2	0.5	0.68
Medication control over asthma	1	3.9	0.8	Ψ
Perceived lack of empathy (PLE)	1	2.3	1.1	Ψ
ADHERENCE (coping procedure)				
Active nonadherence (AnA)	2	2.8	1.01	0.70
Passive nonadherence (PnA)	2	2.4	0.9	0.62
APPRAISAL PROCESSES				
Perceived effect of medication on symptoms PEMS	1	3.7	1.03	Ψ
Self-rated health (n=48)	7	2.6	0.8	0.84
PEFR (%)	Ψ	81.8	20.4	Ψ

Ψ = not applicable

Note: For ease of comparison scale scores have been adjusted by dividing by number of scale items

Table 8.9 Spearman correlations between BMQ-Specific and BMQ -Steroid scales

		1 Specific-Necessity	2	3	4	5
2	Steroid-Necessity	.56**				
3	Specific-Concerns	.28*	.41**			
4	Steroid-Concerns	.26*	.29*	.75**		
5	General-Harm	-.04	.10	.13	.13	
6	General-Overuse	-.26*	-.04	.04	.11	.29*

*p<0.05 p<0.01

Correlates of Active Nonadherence (AnA)

As can be seen from Table 8.10, statistically significant correlates of AnA were Specific-Concerns (rho =0.3), Steroid-Concerns (rho=0.24), Perceived lack of empathy from doctors and nursing staff (PLE) (rho=0.29) and age (rho=-0.29). Thus, younger patients and those with stronger concerns about their prescribed medication as a whole and steroids were more likely to deliberately adjust or miss-out doses of asthma medication, as were those who believed that doctors and nurses did not appreciate what it is like to have asthma (PLE).

Correlates of Passive Nonadherence (PnA)

Patients were likely to report forgetting to take their asthma medication if they held weaker beliefs in the necessity of prescribed medication (lower *Specific-Necessity* scores) or thought that their asthma would be an illness of short duration, (lower *Timeline* scores), which was caused by diet. PnA was also correlated with younger age Also patients who believed that control over their asthma was dependent on medication were less likely to forget to take it. In the sub-set of patients who completed the Self-Rated Health scale, those who rated their health as better, forgot to take their medication more frequently.

Table 8.10 Spearman correlation coefficients of self-reported Active(adjusting dose) and Passive (forgetting doses) medication non-adherence in a sample of patients attending an asthma out-patient clinic (n=78)

Variable	Frequency of AnA (higher scores = higher frequency of adjusting)	Frequency of PnA (high scores = higher frequency of forgetting)
MEDICATION BELIEFS		
Specific Necessity	-.06	-.32**
Specific-Concerns	.30**	.05
Steroid-Necessity	-.08	-.20
Steroid-Concerns	.24*	.05
General-Overuse	.07	.16
General-Harm	.16	-.02
ILLNESS BELIEFS		
IPQ-Identity	-.04	-.03
IPQ-Attributions	-.01	.04
IPQ-Timeline	.02	-.31**
IPQ-Consequences	-.01	.02
IPQ-Control/Cure	.16	.08
IPQ-Causal beliefs		
chance	-.01	-.06
other people	-.05	.07
inherited	-.03	.08
stress	-.06	-.15
diet	.04	.27*
pollution	.07	.03
own behaviour	.07	.18
germ or virus	.11	-.11
Perceived Control Over Asthma (PCA)	.06	.06
Medication Control Over Asthma (MCA)	-.07	-.28*
Perceived lack of empathy (PLE)	.29*	.20
SUBJECTIVE APPRAISAL		
Perceived effect of medication on symptoms PEMS	-.10	-.19
Self-rated health (n=48)	-.07	.28*
CLINICAL OUTCOME		
PEFR (%)	.01	.15
DEMOGRAPHIC VARIABLES		
Age	-.29*	-.51**
Gender	-.20	-.25
Educational experience	.04	.12
Number of prescribed medicines	-.02	-.22
Duration of diabetes (years)	.11	-.16

*p<0.05 **p<0.01

Key predictors of reports of passive and active non adherence to medication

These were identified from the results of two multiple linear regression analyses, using AnA (see Table 8.11) and PnA (see Table 8.12), as the respective dependent variables. Intentional nonadherence was predicted by perceived lack of empathy from medical and nursing staff, concerns about the prescribed medication as a whole and younger age. Together , these variables explained 22% of the variance, with Specific-Concerns alone accounting for 8% of variance in AnA. The reported tendency to forget to take medication was predicted by younger age and weaker beliefs in the necessity of asthma medication for maintaining health, with these variables explaining 33% variance in PnA.

Table 8.11 Linear regression model using AnA as the dependent variable

Variable	B	SE B	Beta	T	Sig T	Cumulative R^2
Perceived lack of empathy	.40	.20	.22	2.00	<.01	.09
Specific-Concerns	.14	.05	.28	2.60	<.01	.17
Age	-.03	.01	-.24	-2.21	<.05	.22

Table 8.12 Linear regression model using PnA as the dependent variables

Variable	B	SE B	Beta	T	Sig T	Cumulative R^2
AGE	-.05	.01	-.49	-5.0	<.01	.28
Specific-Necessity	-.13	.06	-.22	-2.3	<.05	.33
(Constant)	9.6	1.2		8.3	<.01	

8.3.3 Discussion

The major predictors of both active and passive nonadherence were patients' age and personal beliefs. The finding that age and medication beliefs were correlated with reported adherence in the asthma sample was reported in Study 1 in this chapter. The present study augments this earlier analysis by identifying the differential predictors of two forms of adherence behaviour. Whereas younger age was associated with both types of adherence behaviour, the salient beliefs differed according to PnA and AnA. This exploratory study has considerable limitations which are discussed in more detail below. However, it is one of the first to investigate associations between representations of illness, beliefs about medication and active and passive nonadherence to medication. The findings will be discussed under the following headings:

Interrelations between medication and illness beliefs Interactions between the identity, timeline , consequences and cure/control components of asthma representation were similar to those noted in previous studies (Moss-Morris et al. 1996; Petrie et al. 1996; Weinman et al. 1996). Similarly , associations between illness and medication beliefs suggest that patients' ideas about illness and treatment were logically connected. The use of a modified form of the BMQ to assess patients beliefs about steroids, provided an opportunity to evaluate the contribution of beliefs about an individual component to beliefs about the regimen as a whole. Correlations between BMQ-Specific and Beliefs about Steriods scales suggest that, in responding to the BMQ-Specific scales, patients are presenting a view of their prescribed regimen which is a composite of beliefs about individual components. It is interesting that steroids seem to make a greater contribution to regimen concerns than to regimen necessity beliefs accounting for approximately 30% of the variance in *Specific-Necessity* beliefs and 56% of the variance in *Specific-Concerns* about the prescribed asthma regimen. The relative contribution of beliefs about steroids to perceptions of the asthma regimen as a whole is discussed in more detail in, Chapter 9, Study 2. The interaction between illness representation, control beliefs and representations of prescribed medication is discussed in Chapter 9, Study 5.

The effect of age on adherence

The relatively strong associations between age and adherence in this sample were also noted among other illness groups as discussed earlier in this Chapter. It is particularly interesting that the effect of age on adherence was independent of medication beliefs. In this sample age did not correlate with Specific-Concerns (rho=-0.1; n=78; p>0.1) or Specific-Necessity (rho=.13; n=78; p>0.1) beliefs. Moreover, controlling for Specific-Necessity beliefs had a negligible effect on the relationship between age and PnA reducing the Spearman correlation coefficient from 0.51 to 0.49. The finding suggests a direct effect of age on adherence. Further studies are now needed to explore the mechanism of this interaction. In particular this might test the exploratory hypothesis suggested in Study 1 of this Chapter, that elderly patients tend to have a more cautious approach to illness management (Leventhal E, A. in press, Leventhal E, A, 1993 a,b).

Active non adherence This was associated with stronger concerns about asthma medication and perceived lack of empathy (PLE) from medical and nursing staff. The data suggest that patients with strong concerns about long term effects and the potential for dependence attempt to reduce the perceived dangers by taking less. This appears consistent with a self-regulatory approach to medication taking.

If the PLE construct is interpreted as a marker of dissatisfaction with the HCP-patient relationship, then the observed relationship with reported AnA is consistent with a communication model of non-adherence in which dissatisfaction demotivates the patient toward the therapy (Ley and Llewellyn, 1995). Alternatively, agreement with the statement: *'Doctors and nurses do not know what if feels like to have asthma'* might simply indicate a more independent approach to the management of the illness in which the patient perceives their own judgement and experience to be much more pertinent than the advice of HCP who cannot know 'what it is like' to experience the condition. It is reasonable to assume that such a view might be associated with a tendency to adjust the use of medication in line with personal beliefs rather than to simply follow the 'doctor's orders'. One might also surmise that this approach would be associated with high internal control beliefs, with patients seeing their own actions as influential in determining whether their asthma gets better or worse . However, in these data relationships between beliefs about control over asthma and AnA did not reach statistical significance and although they were in the predicted direction -with high internals reporting greater AnA- correlations were minuscule (rho=.06).

Passive nonadherence Patients beliefs about illness and treatment were also related to PnA. A direct relationship between beliefs and AnA is predicted by self regulatory theory but it might seem surprising that beliefs were also related to the reported frequency of forgetting to take medication. Patients reported that they forgot to their medication more frequently if they saw their asthma medication as less necessary or if they thought that asthma would be an illness of short duration which was caused by diet. One interpretation of this finding is that an important determinant of PnA was the perceived *salience* of medication. The correlates of PnA imply that patients had made a decision about the importance of their medication and those patients who thought that medication was less important , forgot to take it more often than those who believed it was salient to their health status.

Control beliefs The relationship between control beliefs and medication adherence is worthy of mention. Beliefs about control over asthma were not significantly related to adherence to asthma medication, which was more strongly associated with beliefs that *medication* controlled whether asthma got better or worse. This finding is consistent with current thinking in relation to locus of control beliefs which are thought to become more predictive with increasing specificity as discussed in Chapter 3 (Furnham and Steele, 1993).

Perceived salience of medication The perceived salience of medication appears to be based on a logical amalgamation of beliefs about the necessity of medication and beliefs about the degree to which control of asthma depends on medication, as well as views about the duration and cause of asthma. The notion of perceived salience may also explain the fact that patients with higher self-rated health reported higher rates of PnA. Patients' who see their health as relatively good think of their medication as less important. The idea that relations between illness beliefs and PnA might operate through beliefs about the salience of medication is given credence by the fact that only Specific-Necessity beliefs and age were retained in the regression model and is further corroborated by correlations between *Specific-Necessity* beliefs and medication control over asthma (rho=0.50; n=78; $p<0.01$), self-rated health (rho=-0.56; n=46; $p<0.01$) and the relevant illness cognitions: timeline (rho=-0.50; n=78; $p<0.01$) and dietary causal attributions (rho=-0.04; n=78; $p>0.1$), though the later relationship was small and statistically insignificant.

Peak expiratory flow rate (PEFR) This was selected as an indicator of clinical outcome because it is the routine measure of disease severity used by the asthma clinic which hosted the research However, although there was considerable variance in the reported frequency of active and passive nonadherence, this was not significantly related to PEFR. This might be because levels of nonadherence were insufficient to reduce the clinical benefit of the medication or that patients were correct in their judgement of optimal intake of medication. However, these findings should be interpreted with caution as there is increasing scepticism about the validity of single time-point determinants of peak flow as a measure of disease severity and as accurate predictors of morbidity and mortality (Clark et al. 1992; Apter et al. 1994).

Leventhal's self-regulatory theory How do these findings relate to the SRM? The fact that adherence behaviours were associated with patients' cognitive representations. is in keeping with the main principles of self-regulatory theory as applied to medication adherence (Leventhal et al. 1992). However, several of the findings appear to be at odds with a literal interpretation of the model. First, medication beliefs were more strongly related to both active and passive nonadherence than illness representations. Second, the appraisal process, operationalised here as perceived effects of mediation on symptoms and self-rated health, was not related to adherence. The observation that medication beliefs were clearly related to adherence is consistent with those reported in previous sections of this chapter and together suggest that the explanatory power of the SRM may be

enhanced by the inclusion of treatment beliefs. This issue will be discussed in greater detail in the concluding chapter of this thesis.

Limitations of the study The results of this study should be interpreted with caution. The difficulties of operationalising Leventhal's complex, model which specifies dynamic interactions between illness cognitions behaviour and appraisal process were alluded to in Chapter 4. It is particularly difficult to capture such dynamic psychological interactions in a simple, exploratory cross-sectional study such as this. Although representations of asthma were assessed using a validated questionnaire (Weinman et al. 1996), other measures were less stringent. Beliefs about control over asthma were assessed using a questionnaire which was designed and validated as a measure of control over recovery from physical disability such as a stroke or orthopaedic fractures (Partridge and Johnston, 1989). Although the adapted questionnaire used in this study was considered to have face validity and had an acceptable degree of internal validity in this sample, it has not been fully validated as a measure of control over asthma.

Similarly, the indicators of subjective appraisal used in this study are of questionable validity for this purpose. Subjective appraisal was conceptualised as the perceived effect of medication on well being. It was assumed that responses to the statement 'Whether I feel better or worse depends on my medicines" would provide an indication of perceived symptomatic effect of medication on symptoms (PEMS). Self-regulatory theory posits that the subject appraisal of symptoms strongly influences the construction of cognitive and emotional representations and provides a framework for the selection and evaluation of coping procedures. However, the operationalisation of patients' subjective appraisal of the effects of medication in asthma may be based on a range of factors of which PEMS is only one. For example a patient may recognise that the steroid component of their medication regimen is designed to prevent worsening of the asthma, rather than to relieve symptoms. Thus, it is possible that important aspects of the appraisal process were not included in the simple single PEMS item used in this study. It may be that the beliefs about medication control over asthma construct could be interpreted as a component of appraisal and this was related to adherence. Similarly, the inclusion of self-rated health as an appraisal indicator can be criticised because this measure was added as an after-thought approximately half way through the study. This was included as a measure of outcome following the observation of a clinician colleague that PEFR measurements, although routinely used as a marker of disease severity, were being subjected to increasing criticism as discussed above. The available data, in which SRH was correlated with *Specific-Necessity*

beliefs and directly with PnA suggest that SRH forms part of a cognitive appraisal of the salience of medication.

8.3.4 Conclusions

Despite its limitations, this study provides preliminary evidence that adherence to medication in asthma is influenced by patients' beliefs about their medication and illness. Patients' cognitive models of their illness were associated with their views about medication which in turn influenced their reported usage of it. It is significant that beliefs were related to the frequency of forgetting medication as well as to more active non-adherence. The tendency to deliberately adjust the medication regimen , outside the instructions was associated with stronger concerns about the medication, providing further evidence that AnA may be a strategy to minimise harm by taking less. The pattern of correlations between beliefs and reported behaviour are consistent with the notion that patients' beliefs about their illness and treatment are important determinants of adherence behaviour as suggested by self-regulatory theory.

CHAPTER 9
The determinants of medication beliefs

The identification of core dimensions of beliefs about general and specific medication and the finding that medication beliefs were associated with adherence to medication, raises questions about their determinants. A decade ago, Marteau and Johnston (1986a) suggested the need to "ascertain the factors that influence the formation of beliefs that are the target for change." Representations of illness and treatment are developed within a social and cultural context. There is now increasing interest in the degree to which illness beliefs are influenced by contextual variables such as age, gender, educational experience and other socio-cultural factors. Several authors have suggested that knowledge of the determinants of beliefs might inform the development of models explaining the interaction between beliefs, behaviour and outcome (Leventhal et al. 1997). Yet, with a few notable exceptions (e.g. Marteau and Johnston, 1986a), relatively few studies have explicitly set out to systematically identify the determinants of health-related cognitions. However, enough evidence has accumulated as a "by-product" of research focusing on the nature or effects of health cognitions to suggest that socio-demographic characteristics factors may influence cognition and behaviour. For example, Elaine Leventhal and colleagues (1993a) described approaches to health problems and care seeking behaviour which appear to be characteristic of older patients. In another study of representations of health illness and medicines in general among residents of the Basque Country, older patients were more likely to have a more positive attitude to medication in general than their younger counterparts (Echabe et al. 1992). However, other studies failed to demonstrate a significant relationship between age and health beliefs (Lim et al. 1994), attitudes to tranquillisers (Clinthorne, 1986) or asthma medication (Osman et al. 1993).

Although gender related differences in symptom reports and consultation rates have been noted (Leventhal E, A. 1993a; Nerenz et al. 1986; Prohaska et al. 1987; Prohaska et al. 1985), none of the studies mentioned here has identified a consistent statistically significant link between gender and health beliefs. Conversely, existing research suggests that professional status (e.g. lay versus medical) (Marteau, 1990), educational experience (Echabe et al. 1992; Lim et al. 1994), type of illness (Weinman et al. 1996), cultural origin (Morgan and Watkins, 1988), trait characteristics such as mood (Croyle and Ditto, 1990) and experience of the illness in question (Marteau and Johnston, 1986a), may be important determinants of beliefs about illness and treatment.

The aim of this final section of the experimental work was to identify some of the determinants of specific and general medication beliefs. Several studies were therefore conducted to investigate whether socio-demographic variables (gender, age and educational experience) were related specific and general medication beliefs. Additionally the impact of other cognitions such as beliefs about sensitivity to medication, and beliefs about illness was evaluated. Studies were conducted at two levels. The first was exploratory, examining interactions between individual variables and BMQ factor scores. This was followed by a further analysis, using multiple linear regression to identify the effect of combinations of determinants in explaining variance in the core dimensions of medication representation. A further, preliminary investigation of the relationship between medication beliefs and self-report measures of previous and current experience of medication side-effects was also conducted.

9.1 Demographic variables and medication beliefs

This study assessed the relationship between age, gender and educational experience on specific and general beliefs about medicines.

9.1.1 Method

Participants The 6 chronic illness groups comprising the main sample described in Section 6.3:

Measures

- The Beliefs about Medicines Questionnaire (BMQ) (in Section 7.2.1).
- Patient demographic details: age, gender and educational experience assessed as in Section 6.4.9.

Procedure:

The data collection procedure is described in Section 6.5.

Statistical techniques

- Relations between Gender and BMQ Specific and General scale scores were investigated using Mann Whitney U
- The effect of age on BMQ Specific and General scale scores was investigated using Spearman correlation.

- One way Analysis of Variance with Post Hoc Tukeys HSD test was used to examine the influence of educational experience on BMQ Specific and General scale scores. Multivariate analysis of variance (MANOVA) was not used for analysis of differences in measures due to the moderate level of intercorrelation between *Specific-Concerns* and *General-Harm* (rho=0.31; n=524; p,0.01) and *General-Overuse* (rho=0.24; n=524; p,0.01).

9.1.2 Results

Gender There was no significant relation between gender and BMQ factor scores within the data set at the global or individual diagnostic group level.

Age Spearman correlations between BMQ scores and age of the subject are shown in Table 9.1. The influence of age on medication beliefs was modest and limited to certain diagnostic groups. For example, in the pooled data set, age had a small but statistically significant effect on general beliefs about medicines with older patients having a weak tendency to attain higher scores on the *General-Harm* sub-scale. At the single diagnostic group level, this relationship was only noted among psychiatric out-patients. However, age on the *General-Harm* scores was small, accounting for only 4% of the variance in this dimension

Table 9.1 Spearman correlations between age and BMQ factors for various diagnostic groups

	Group total n =524	Asthma	Diabetes	Dialysis	Cardiac	Psychiatric	General-Medical
Specific-Necessity	-0.05	0.13	-0.35**	-0.08	0.07	0.01	0.11
Specific-Concerns	-0.08	-0.01	0.16	-0.16	-0.26**	0.04	-0.05
General Harm	0.12**	0.09	0.11	0.12	0.07	0.22*	0.18
General-Overuse	0.08	0.05	0.14	-0.22	0.03	0.03	0.03

* $p < 0.05$; ** $p < 0.01$

The relationship between age and BMQ-Specific scores was inconsistent. No significant correlations were found between age and specific medication beliefs in the combined data set but, on conducting the analysis in individual diagnostic groups, a mixed picture

emerged. Younger cardiac patients were more concerned about the potential adverse effects of their prescribed medication as indicated by the negative correlation between age and *Specific-Concerns* (rho = -0.26; n=116; p<0.01), but this effect was not noted in other diagnostic groups. Younger diabetic patients had stronger beliefs in the necessity of their treatment (rho = -0.35; n=99; p<0.001). This sample comprised insulin treated (n=64) and tablet treated (n=35) diabetics and the effect of age on *Specific Necessity* beliefs ceased to be statistically significant after controlling for treatment.

Educational experience Data on educational experience was not available for the diabetic sample and a further 12 cases were omitted from the subsequent analysis because this aspect of the demographic data sheet had not been completed. A final sample of 408 patients (211 male) from several diagnostic groups (asthma n = 75; dialysis n = 47; cardiac n = 113; psychiatric n = 88 and general medical in-patients n = 85) was included in a one-way analysis of variance, of BMQ factors by educational experience, as secondary (n=190); tertiary (n=155); higher (n=63). A post-hoc Tukey's HSD showed that no two educational groups were significantly different at the 0.05 significance level on the *Specific Necessity*, *Specific-Concerns* or *General-Overuse* scales. However, educational status was significantly related to scores on the *General-Harm* factor (p<0.001). People educated to tertiary level were less likely to have a prototypic view of medication as harmful, whereas patients educated to secondary level or below tended to have stronger beliefs that medicines are "harmful, addictive poisons".

9.1.3 Discussion

The finding that gender was not related to medication beliefs is consistent with previous work which has failed to establish a direct link between gender and health beliefs. Similarly, age per-se had little effect on beliefs about prescribed medication with the exception of the cardiac sample. Younger patients with chronic cardiac disease had stronger concerns about their prescribed medication. *Specific-Concerns* arise from beliefs about the potential of prescribed medication to cause dependence and long-term effects, and a representation of medication as disruptive and mysterious. One explanation for this finding is that these issues would be far more salient for younger patients. If this were so then why was this relationship not noted in other groups? The answer to this question may lie in the fact the cardiac group had a broad age range (21 to 86 years) and a significantly higher mean age than all groups. (One-way analysis of variance with post-hoc Tukey's HSD p<0.001). This result implies that *Specific-Concerns* become less salient in older age. This is logically consistent with the individual beliefs which comprise this representation. However, further

studies in other samples are needed to verify this finding and support the explanatory hypothesis.

The effect of age on *Specific Necessity*, limited to the diabetic sample, appears to be an artefact arising from age-related differences in type of treatment. Younger patients, who had stronger beliefs in the necessity of their treatment were predominantly treated with insulin as opposed to oral hypoglycaemic agents which were more commonly prescribed for older patients. An explanatory hypothesis is that insulin-treated diabetics perceive their illness as more severe and consequently see their treatment as more necessary than tablet-treated patients. This sample also completed the Illness Perceptions Questionnaire (IPQ) (Weinman et al. 1996), which assess the components of illness representation, described by Leventhal (Leventhal et al. 1992a; Leventhal and Nerenz, 1985; Leventhal et al. 1980). Thus, the explanatory hypothesis could be tested in that higher timeline, identity and consequence scores would be consistent with this explanation. As expected, insulin-treated patients had significantly stronger Identity scores ($t = 2.26$; $df = 84$; $p<0.05$), perceived their illness as more chronic (higher Timeline scores: $t = 4.27$; $df = 96$; $p<0.001$) with more severe consequences (higher Consequences scores: $t = 3.78$; $df = 77$; $p<0.001$) than tablet-treated patients. Moreover, the correlation between age and specific-necessity beliefs was not statistically significant after controlling for Timeline and Consequence scores. This finding, and that obtained in the cardiac sample, provide a preliminary insight into the determinants of medication beliefs. It seems that any differences in medication beliefs associated with age arose from a logical "common-sense" interpretation of age-related differences in illness and treatment, rather than differences in cognition which arise as a direct effect of ageing. Although, further studies are needed to test the generalisability of this finding it is consistent with the view of the patient as a rational 'problem solver' (Leventhal and Diefenback, 1991).

The pattern of relationships between demographic data and beliefs about medicines in general is almost identical to that obtained by Lim, Schwarz & Lo (1994) who investigated the prevalence of "traditional" Chinese health beliefs in a sample of over 900 Hong Kong Chinese. Age and gender did not influence beliefs but those with less formal education were more likely to have stronger Chinese health beliefs. In the present study, patients with less formal education had a more negative view of medication. It may be that formal education leads to a more positive orientation to "western" biomedicine with its emphasis on drug treatment of disease and away from a more traditional "folk" interpretation of health and illness such as those described by Patcher (1994). However, it should be noted

that the effect of educational experience on general medication beliefs was small. Clearly, age on finishing full time education is a proxy measure of educational experience as people may continue their education on a part-time basis. Thus this measure might under-estimate educational experience which in turn might have obscured a stronger relationship between education and general views about medication. The impact of social class or occupation upon medication beliefs was not evaluated, and is a target for future research.

In conclusion, this study suggests that, demographic variables are not strong determinants of beliefs about specific or general medication. Rather, a close examination of the findings hints that medication beliefs may be more strongly influenced by other cognitions arising from characteristics of the illness and treatment, than by demographic variables. The role of cognitions as determinants of medication beliefs is explored in more detail in further studies described below.

9.2 Effect of the type of illness and number of prescribed medications on medication beliefs

Fallsberg, in her qualitative study of conceptions of medication among three groups of Swedish patients, noted that certain representations seemed to be associated with particular illness and treatments. In particular, she noted the propensity of asthma patients to worry about the potential adverse of cortisone (Fallsberg, 1991). Other studies indicate that the number and dose of prescribed medications might affect perceptions of illness severity (Donovan and Blake, 1992) and it is interesting to question whether this relationship might be extended to representations of medication.

Aims of the study

1. To examine whether the characteristic features of particular illnesses and their associated treatments might influence patients' perceptions of medication and whether the effect on *Specific* beliefs would be more profound than on *General* beliefs.
2. To investigate whether the number of medicines prescribed for the patient were related to beliefs about specific or general medication.

9.2.1 Method

Participants

- The 6 chronic illness groups comprising the main sample described in Section 6.3.

•

Measures

- The Beliefs about Medicines Questionnaire (BMQ) (described in Section 7.2.1).
- Number of medicines prescribed for the patient.

Data on the number of prescribed medicines were obtained from two sources. For hospitalised patients (the renal, cardiac and general medical inpatient samples), information on the number of medicines prescribed was obtained from the medical notes and prescriptions chart. For the out-patient clinic samples (asthma and psychiatric samples) details about prescribed medication were obtained by asking the patient as the medical notes were being used by the clinic consultant. Accurate details of the number of medicines used by the diabetic were not available. However the clinic pharmacist reported that the majority of patients were prescribed only medication for their diabetes (insulin or a single oral hypoglycaemic agent.

Procedure

The data collection procedure is described in Section 6.5.

Statistical techniques

- Differences between BMQ- Specific and General scores across illness samples were assessed using a series of one-way analysis of variance (ANOVA), followed by post-hoc Tukey's HSD test. Multivariate analysis of variance (MANOVA) was not used for analysis of differences in measures due to the moderate level of intercorrelation between *Specific-Concerns* and *General-Harm* (rho=0.31; n=524; p,0.01) and *General-Overuse* (rho=0.24; n=524; $p<0.01$).
- Relations between the number of prescribed medicines and the BMQ-Specific and General scales was examined using Spearman correlation.

There was a possibility that any associations between medication beliefs and number of medicines would be confounded by recall bias. Patients who think their prescribed medication is more important or are more concerned about its potential harmful effects may recall more of them. In order to control for this, correlations between BMQ scores and number of medicines were examined in two ways: first as a total sample of 5 illness groups (asthma, renal, cardiac, general medical and psychiatric samples), then separately according to whether information about number of prescribed medicines was obtained from the medical notes (hospital inpatients: renal, cardiac and general medical) or patient recall (asthma and psychiatric clinic samples).

9.2.2 Results

Type of illness/treatment and medication beliefs: One way analysis of variance with post-hoc Tukey's HSD, revealed significant differences in BMQ-Specific scores according to diagnostic group. These data were used as evidence for the discriminant validity of the BMQ and are provided in Table 7.12. However for ease of reference, these data are repeated in Table 9.2 and as box plots in Figure 9.1 The diabetic group had significantly higher *Specific-Necessity* scores than all other groups and the asthma patients had significantly higher scores than the psychiatric outpatients who attained the lowest mean *Specific-Necessity* score of all the groups. Asthma and psychiatric patients also had significantly higher scores on the *Specific-Concerns* scale. Diabetic patients who, as a group had higher scores on the *Specific-Necessity* scale were also significantly less likely to believe that medicines in general were overused by doctors (*General-Overuse*) than did patients with chronic heart disease or general hospital inpatients ($p<0.05$). Conversely beliefs about the general nature of medicines as opposed to how they are used by doctors (*General-Harm*), were independent of type of illness.

Number of prescribed medicines The effect of number of prescribed medications on beliefs about medicines was evaluated in the asthma , renal, cardiac psychiatric general medical inpatients groups. The number of medications was positively correlated with *Specific Necessity* beliefs ($rho=0.38$; $n=399$; $p<0.01$), but there was no significant relationship with other BMQ factors. Considered separately as hospital (renal, cardiac and general medical) and clinic (asthma, psychiatric) samples, correlations between *Specific-Necessity* and number of prescribed medicines were significant for both the hospital group where information on the number of medicines was obtained from the medical notes ($rho=0.32$; $n=238$; $p<0.01$), and the clinic group where information was recalled by the patient ($rho=0.49$; $n=161$; $p<0.01$).

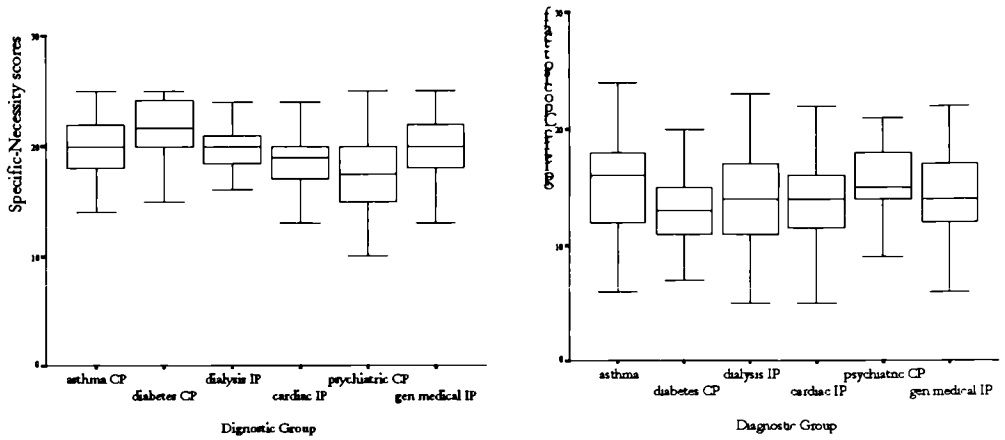
Table 9.2 Scale means and standard deviations for BMQ scales for the six illness groups comprising the main sample

Scale	Asthma n=78	Diabetes n=99	Renal n=47	Cardiac n=116	Psychiatric n=85	General Medical n=86	F df= 5,505	p
Specific-Necessity								
Mean	19.67_{b}	21.26_{a}	$19.45_{b,c}$	$18.72_{b,c}$	17.72_{c}	19.65_{b}	11.73	<0.01
SD	3.23	2.98	2.78	3.02	3.75	3.92		
Specific-Concerns								
Mean	15.76_{a}	12.91_{c}	$13.77_{b,c}$	13.95_{c}	$15.60_{a,b}$	$14.26_{a,c}$	7.49	<0.01
SD	4.09	3.38	4.28	3.73	3.36	3.92		
General-Harm								
Mean	10.24_{a}	9.29_{a}	9.91_{a}	9.98_{a}	9.92_{a}	9.86_{a}	1.29	0.26
SD	2.30	2.43	3.76	2.32	2.81	2.80		
General-Overuse								
Mean	$11.64_{a,b}$	11.43_{a}	$12.66_{a,b}$	12.80_{b}	$12.25_{a,b}$	$12.42_{a,b}$	3.48	0.01
SD	2.59	2.77	3.19	2.90	2.84	2.76		

Note: Means sharing a common subscript are not significantly different by HSD test (p>0.05).

9.2.3 Discussion

The observed interactions between type of illness and medication beliefs are salient when one considers the type of medication prescribed for each illness and its likely effect on symptoms. For example, diabetic patients who had significantly higher *Specific Necessity* scores than all other groups, are usually aware that, without treatment (insulin or oral hypoglycaemic agents), their condition will deteriorate rapidly. The finding that asthma patients had stronger *Specific Necessity* beliefs than psychiatric out-patients might be partially attributed to the perceived relationship between medication taking and symptoms. Leventhal, H and Leventhal, E (1993) have pointed out the importance of concrete symptom experience in guiding peoples' representations of illness and this might also be true for representations of prescribed medication. Each of these conditions tends to produce very different concrete symptom experiences in relation to medication. Symptom relief in asthma can often be closely linked to using prescribed medication. Similarly, omitting medication may quickly result in adverse symptoms. Conversely, patients receiving medication for mental health related problems may perceive a much more tenuous link between their medication and concrete benefit in terms on symptoms. Conclusions from these data are clearly tentative and more work is needed to complete our understanding of how symptom experience and medication representations are related.



CP = Hospital oupatient clinic patient

IP = Hospital inpatient

Figure 9.1 Comparison of *Specific-Concerns* and *Specific-Necessity* scores between diagnostic groups

Variations in scores on the *Specific-Concerns* scale across diagnostic groups might also be explained by the perceived characteristics of specific types of medication, used in the treatment of these conditions. Asthma patients had the highest scores on this scale, followed in close second place by psychiatric outpatients. Asthma treatment often incorporates corticosteroids. Steroids are a large group of compounds, some of which may produce adverse side effects. Additionally, other members of this group are frequently misused in sport. In short, this class of drugs has a high "media-profile" and patients' concerns might be influenced by this, particularly if they fail to differentiate between steroids they are taking for asthma (which are generally inhaled and therefore less "dangerous") and more potent formulations upon which media attention is often focused. This explanation is supported by the finding that in this sample, concerns about steroids were particularly salient, explaining over 50% of the variance in concerns about the asthma regimen as a whole, as detailed in Chapter 8, study 3. Moreover, a recent study has also identified worries about steroids as a cultural determinant of treatment use in asthma (Hand and Bradley, 1996). This idea can also be extended to help explain higher concern in the psychiatric out-patient sample, as these patients are often treated with "tranquillisers", which have also received adverse media attention (Cohen, 1983). The notion that patients' cognitive representations of medication arise, at least in part, from a logical interpretation of perceived characteristics and effects of specific medication is reinforced by the finding that scores on the *General-Harm* scale were not influenced by the type of illness. This scale

assesses beliefs about the harmful nature of medicines in general rather than medication prescribed a particular illness.

In conclusion, the findings support the hypothesis that the illness and treatment influences representations of prescribed medication. The observation that *Specific Necessity* beliefs were positively correlated with the number of medicines prescribed concurs with previous reports that patients may interpret the number of prescribed medication as markers for disease severity or treatment necessity (Donovan and Blake, 1992; Morgan and Watkins, 1988; Leventhal et al. 1991). Moreover, this relationship was held in the hospital samples where data were obtained from the medical notes -supporting the premise that it is a true effect, rather than a confounder arising from recall bias.

In summary, the present study provides tentative support for the role of the perceived characteristics of the treatments associated with particular illnesses as determinants of medication beliefs. It also focuses attention on the possible role of perceived adverse or beneficial effect of medication upon symptoms as a determinant of beliefs about prescribed medication. A related question is whether the level of concern about prescribed medication is related to beliefs about personal susceptibility. These questions were addressed in Study 3 which is described below.

9.3 The role of beliefs about personal susceptibility to the adverse effects of medication and perceived effects of medication on symptoms

This study set out to explore the role of two aspects of cognition as antecedents of medication representations. These are detailed below, together with a brief rationale for their inclusion in the study:

Perceived effect of prescribed medication on illness symptoms

Pennebaker (1982), has shown that illness-related cognitions and the interpretation of physical symptoms are closely related . Also, self-regulatory theory suggests that illness representations and the selection and appraisal of coping procedures are influenced by current and past experience of symptoms, and there is evidence to support this (Gonder-Frederick and Cox, 1991; Love et al. 1989; Leventhal et al. 1986). Thus, it is salient to question whether representations of medicines might also be influenced by their perceived effects on symptoms. In particular, it might be anticipated that a perception that prescribed

medication made one "feel better" by improving symptoms would result in stronger beliefs in its necessity. Conversely, one would not anticipate a strong interaction between a patient's perception of how the medication affected the symptoms of their illness and beliefs about the danger of dependence or long-term effects attributed to the medication represented by the *Specific-Concerns* dimension.

Perceptions of personal susceptibility to the adverse effects of medication

The HBM stresses the importance of beliefs and personal susceptibility in the interpretation of health threats (Rosenstock, 1974). In questioning the determinants of concerns about adverse effects of medication, it therefore seems apposite to examine the role of perceived susceptibility to the adverse effects of medication as health threats.

The study hypotheses were that:

1. *Specific-Necessity* beliefs would be positively influenced by the perceived symptomatic benefit of prescribed medication (i.e. significant positive correlations would be obtained between *Specific-Necessity* and scores on the Perceived effect of prescribed medication on symptoms (PEMS) scale.
2. Patients with stronger beliefs in their personal vulnerability to the adverse effects of prescribed medication would have stronger concerns about medication prescribed for their illness; (i.e. significant positive correlations would be obtained between *Specific-Concerns* and scores on the Sensitive Soma (SS) Scale).
3. The cognitive variables specified in 1 and 2 above (i.e. the PEMS and SS constructs) would be stronger determinants of medication beliefs than patient demographic characteristics (age, gender, educational experience).

9.3.1 Method

Participants

Participants were patients comprising the Cardiac and General-Medical In-patient samples described in Section 6.3.1.5.

Measures

- The Beliefs about Medicines Questionnaire (BMQ) described in Section 7.2.1.
- Perceived effect of prescribed medication on symptoms (PEMS) described in Section 6.4.6.
- The Sensitive Soma scale described in Section 6.4.7.

- Patient demographic details: age, gender and educational experience assessed as in Section 6.4.9.

Statistical techniques

- Relations between BMQ Specific and General scale scores and SS and PEMS scales were investigated using Spearman correlation.
- The percentage variance in BMQ Specific and General scores explained by SS, PEMS and demographic variables was investigated by multiple linear regression using the stepwise entry and removal method, setting probability F for entry an removal at 0.05 and 0.01. The rationale for using this parametric technique with ordinal data (e.g. gender and the BMQ, SS and PEMS scales) is presented in Section 6.6.

Procedure

The data collection procedure is described in Section 6.5. Analyses were performed in two stages. Spearman correlations between the SS scale, PEMS scores and BMQ factors scores were first assessed separately in the cardiac (n=120) and general medical samples (n=91). The relative role of these variables and other factors, such as age, educational experience and number of prescribed medicines in predicting the dimensions of specific and general beliefs about medicines, was then investigated by multiple linear regression analysis of pooled data from both groups. A series of regression analyses were computed using each BMQ factor as the dependent variable. In each cases the three other BMQ factors were entered using a stepwise method along with SS scores, SE scores, age, educational experience, and the number of prescribed medicines.

9.3.2 Results

Frequency distributions of scores on the SS and PEMS scales are shown in Figures 9.2 and 9.3. Spearman correlations between BMQ factor scores, SS scores, PEMS scores and number of prescribed medicines for each diagnostic group are shown in Table 9.3.

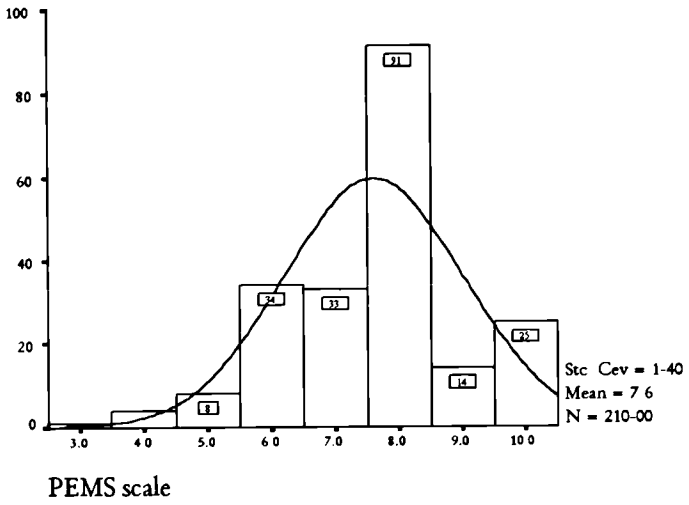


Figure 9.2 Frequency Distribution of scores on the PEMS scale (higher scores = stronger perceptions of symptomatic benefit of prescribed medication)

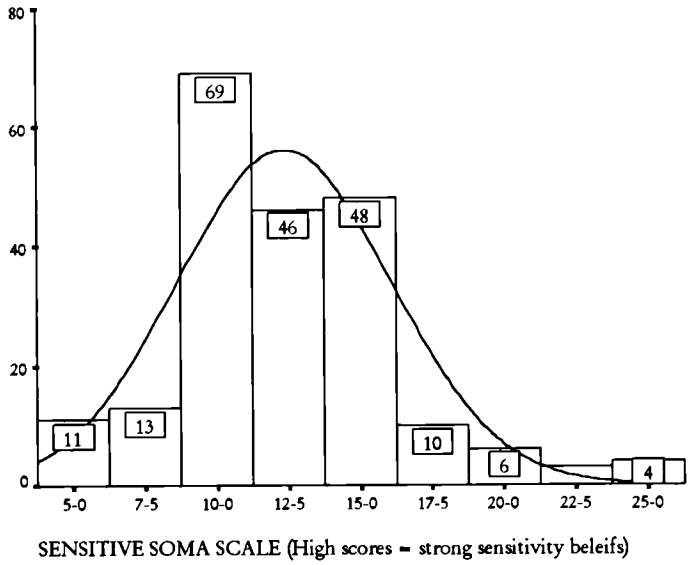


Figure 9.3 Frequency distribution of scores on the Sensitive Soma Scale (cardiac and general medical samples; n= 210)

Table 9.3 Spearman correlations between BMQ factor scores, SS scores and PEMS scores in the general medical inpatients sample (upper-level figures; n=91) and the cardiac sample (lower level figures; n=119)

	Sensitive Soma Scale (SS)	PEMS	Number of medicines prescribed	Specific-Necessity	Specific-Concerns	General-Harm
Specific-Necessity	-.01 -.06	.52** .51**	0.45** 0.19*			
Specific-Concerns	.50** .44**	-0.01 -0.17	0.19 0.11	0.12 0.13		
General-Harm	0.25* 0.22*	-.05 -.14	0.04 0.03	-0.09 -0.04	0.49** 0.39**	
General-Overuse	0.05 0.22*	-.24* --.11	-0.01 0.15	-0.18 -0.2*	0.29** 0.29**	0.40** 0.26**

* $p < 0.05$; ** $p < 0.01$;
PEMS: Perceived Effects of prescribed medication on symptoms scale (higher scores indicating greater perceived effect)
Sensitive Soma Scale: assesses perceptions about personal sensitivity to the adverse effects of medication (higher scores indicating greater perceived sensitivity)

A similar pattern of correlations was obtained for both samples. Significant correlations were obtained between *Specific Necessity* beliefs and the perceived effect of medication on symptoms and the number of medicines prescribed. Perceived sensitivity to the potential adverse effects of medication (SS scores) were related to *Specific-Concerns* about prescribed medication accounting for 19% and 25% of variance in this dimension. SS scores also correlated with more general beliefs about medication, in the predicted direction, but here the relationship was weaker. Correlations between specific and general beliefs about medicines were similar to those reported in the combined data set from 6 diagnostic groups reported in Chapter 7 and show that *Specific-Concerns* were related to *General-Harm* and *General-Overuse* scores.

The fact that a similar pattern of correlations was obtained in both cardiac and general-medical data sets justified pooling the data from both samples for the regression analyses. Table 9.4 shows the results of linear regression analyses using the BMQ factors as the dependent variables and entering the three other BMQ factors, SS scores, SE scores, number of prescribed medicines, age, and educational experience as the dependent variables. The table shows only those variables retained within the model after step-wise entry and removal.

Table 9.4. Linear regression analyses of determinants of beliefs about specific and general medication in pooled data from the cardiac and general medical in-patient samples (n=211)

BMQ factor	Variable	B	SE B	Beta	T	Sig T	Cumulative Adjusted R square
Specific Necessity	PEMS$^{\nabla}$	1.44	.15	.55	9.5	<0.01	.35
	MEDS*	.31	.08	.23	3.9	<0.01	.39
Specific Concerns	Sensitive-Soma	.42	.06	.42	7.14	<0.01	.24
	General-Harm	.44	.08	.31	5.01	<0.01	.34
	Age	-3.7E-02	.01	-.16	-2.80	<0.01	.36
	General-Overuse	.18	.08	.13	2.17	<0.05	.37
General Harm	Specific-Concerns	.27	.05	.38	5.74	<0.01	.16
	General-Overuse	.21	.06	.22	3.28	.<0.01	.21
	Age	2.95E-02	.01	.19	2.89	<0.01	.24
General Overuse	General-Harm	.25	.08	.25	3.31	<0.01	.10
	Specific Necessity	-.12	.05	-.16	-2.37	<0.05	.12
	Specific-Concerns	.11	.05	.16	2.14	<0.05	.14

$^{\nabla}$ Perceived Effect of Medication on Symptoms Scale (PEMS)

* MEDS = number of prescribed medicines

The key determinants of *Specific Necessity* beliefs were the perceived effects of specific medication on symptoms and the number of medicines prescribed for the patient. These variables accounted for 40% of the variance in the *Specific Necessity* dimension. *Specific-Concerns* were determined by perceived sensitivity to the potential adverse of medication (Sensitive Soma scores), and beliefs that medicines in general are harmful, addictive poisons which should not be taken for long periods of time (*General-Harm*). These two cognitive variables alone explained 35% of the variance in *Specific-Concerns*. Adding age and educational experience to the model explained an additional 4% of the variance in this factor. The major determinants of general beliefs about medication also turned out to be other cognitions. *Specific-Concerns* and *General-Overuse* accounted for 22%, with age adding a further 3%, to the explained variance in the *General-Harm* dimension. The determinants of beliefs that medicines are overused by doctors were *General-Harm* and *Specific Necessity* beliefs which accounted for 13% of the variance in the *General-Overuse* factor.

9.3.3 Discussion

Relations between beliefs about prescribed medication (BMQ-Specific) and perceptions of symptomatic benefit (PEMS) and susceptibility to adverse effects (SS) confirmed the study hypotheses. Patients who associated their medication with greater symptomatic benefit had stronger beliefs in its necessity for maintaining health. Patients who perceived themselves to be more sensitive to the potential adverse effects of medicines had stronger concerns about medication which had been prescribed for them. Moreover, cognitive variables such as the perceived effects of medication on symptoms and perceived susceptibility to the adverse effects of medicines were far stronger determinants of the core dimensions of medication representation than were the socio-demographic variables studied. Although age and educational experience were determinants of *Specific-Concerns* and age of *General-Harm* they added little to the explained variance in these dimensions. Moreover, linear regression analyses of the determinants of each of the BMQ factors revealed a logically coherent pattern of interactions between specific and general beliefs about medication and other cognitive variables.

The determinants of each BMQ factor imply that patients' ideas about medication are coherent in "common-sense" terms. For example, patients were more likely to have strong beliefs in the necessity of their medication if it was perceived to affect their symptoms. Similarly, necessity beliefs tended to be stronger with more medicines prescribed. There is evidence that some patients use the number of medicines prescribed for them as an indication of disease severity (Donovan and Blake, 1992; Morgan and Watkins, 1988; Leventhal et al. 1991). Presumably, this in turn, influences the perception of the necessity of their medication. Unfortunately, data on illness representations was not available for the cardiac and general medical samples used in this study and so the validity of this explanation could not be tested. However relations between medication beliefs and the components of illness representation are explored in Section 9.5. One might expect that *Timeline*, *Identity*, *Consequences* and *Cure* scores would be positively correlated with *Specific Necessity* beliefs and would add to the variance in these beliefs which is explained by perceived symptom effects. However, the effect of the number of prescribed medicines may then cease to add significantly to the model, if, as suggested, patients' interpret this as a proxy measure of the severity of their illness.

The key determinants of *Specific-Concerns* were beliefs about the harmful nature of medicines in general (*General-Harm)* and beliefs about personal susceptibility to such effects (Sensitive Soma). The *General-Harm* factor may represent a prototypic view of medication,

analogous to the disease prototypes noted in studies of lay representation of illness (Bishop, 1987; Bishop and Converse, 1986). Thus these concerns about specific prescribed medication are linked to more general beliefs that medicines are intrinsically harmful and perceived vulnerability to there effects.

The frequency histogram of Sensitive Soma scores obtained for the study sample (Figure 9.3) indicates a wide variation in the degree to which patients believe that they are susceptible to the adverse effects of medication. The utility of this scale as a determinant of *Specific-Concerns* about prescribed medication focuses interest on the origin and determinants of Sensitive Soma beliefs. Sensitive Soma representations are grounded in the past experience of adverse medication effects. For example, one of the items asks the respondent to state their level of agreement with the statement "*I have had a bad reaction to medicines in the past*". (In the combined cardiac and general hospital in-patient samples 69% disagreed with this statement, 8% were uncertain and 23% agreed). However, the item to scale correlation is 0.7 indicating that other factors also determine Sensitive Soma beliefs. In this context, it is interesting to speculate whether *Specific-Concerns*, and Sensitive Soma beliefs share an underlying dispositional factor, such as Negative Affectivity (Watson and Pennebaker, 1991).

The relationships between general beliefs about overuse and harm and specific beliefs about prescribed medication were logically coherent. Although, it is difficult to be certain about the direction of influence between general and specific beliefs, the data described is consistent with a multi-directional path. For, example the level of agreement with the notion that doctors overuse medication *(General-Overuse)* was influenced by prototypic views about medicines as essentially harmful (*General-Harm*) but also by beliefs about the necessity of medication which had been prescribed for current use in the treatment of the patient's illness. Conversely, *Specific Necessity* beliefs were not significantly influenced by *General-Overuse* beliefs. The interaction between *Specific-Concerns* and *General-Harm* was bi-directional. This form of interaction between prototypic beliefs and specific beliefs, having experiential and cognitive components, is consistent with self-regulation (Leventhal et al. 1992a).

9.4 The experience of medication side-effects as a determinant of medication beliefs

This study address relations between patients' reported experience of adverse effects attributed to medication and their beliefs about their prescribed medication and about and medicines in general. Self-regulatory theory suggests that illness representations have both abstract and experiential components. The latter, in the form of symptoms are important in the formation of illness representations (Cameron et al. 1993; Baumann et al. 1989). The previous study had shown that concerns about medication were related to abstract ideas about personal susceptibility to the adverse effects of medication. In line with self-regulatory theory one might therefore expect the perceived experience of medication side-effects to influence representations of medication, particularly concerns about prescribed medicines. The present study set out to investigate this question in a sample of oncology patients. Furthermore, data collected on the number of medication and sociodemographic data made it possible to investigate the extent to which inter-relations between BMQ factors and socio-demographic variables described in previous studies above could be confirmed in a sample of oncology patients.

9.4.1 Method

Participants

- The oncology patients described in Section 6.3.2.2.

Measures

- The Beliefs about Medicines Questionnaire (BMQ) described in Section 7.2.1.
- Patient demographic details: age, gender and educational experience assessed as in Section 6.4.9.
- **Current experience of medication side-effects (Present-ESE)** was assessed by responses to the single statement: '*The side-effects of my medication sometimes make me unwell*'. Responses were scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree. Thus higher scores indicate greater experience of side-effects from present medication.
- **Past experience of medication side effects (Past-ESE)** was assessed by responses to the single statement: '*I have experienced side-effects from medication in the past*' Responses were scored on a 5-point Likert scale where 1= strongly disagree, 2 =

disagree, 3 = uncertain, 4= agree and 5 = strongly agree. Thus higher scores indicate greater experience of side-effects from past medication.

Procedure:

The data collection procedure is described in Section 6.5.

Statistical techniques

- Relations between reported experience of side-effects and medication beliefs were investigated using Spearman correlation.
- In order to explore the relationship between *Specific-Concerns* and Present-ESE in more detail a test-for equality of means was conducted on the *Specific-Concerns* sub-scale and a dichotomised version of the Present-ESE scale. (Group 1=strongly agree/agree; Group 2= uncertain/disagree/strongly disagree).

9.4.2 Results

Scores on the BMQ sub-scales and experience of side-effects statements are shown in Tables 9.5 and 9.6 below.

Table 9.5 Profile of BMQ scores and response to side effect statements

	BMQ-scale mean	SD	Respondents with > mid-point scores
Specific Necessity	19.9	3.3	93%
Specific-Concerns	13.2	3.8	24%
General-Harm	10.0	2.7	13%
General-Overuse	12	2.5	40%

Table 9.6 Percentage responses to statements eliciting perceived experience of side-effects

Experience of side-effects (ESE)	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
The side-effects of my medication sometimes make me unwell (Present-ESE)	13.3	50.6	6.0	21.7	8.4
I have experienced side-effects from medication in the past (Past-ESE)	8.0	44.8	4.6	36.8	5.7

Note: some of the questionnaires were not entirely complete and correlations were computed using the available data. Thus for some tests, the number of subjects is less than the total sample (n=91).

A significant positive correlation was observed between Present-ESE scores and *Specific-Concerns* (rho = 0.34; n=81; p<0.005), but with no other BMQ factor. No significant interactions were observed between Past-ESE and any of the BMQ factors.
In order to explore the relationship between *Specific-Concerns* and Present-ESE in more detail a test-for equality of means was conducted on the *Specific-Concerns* sub-scale and a dichotomised version of the Present-ESE scale. (Group 1=strongly agree/agree; Group 2= uncertain/disagree/strongly disagree). Patients in Group 1 had significantly higher mean *Specific-Concerns* scores than those in Group in 2 (14.1 vs 11.6, t = -3.1; df = 79; p<0.005).

In this study an interesting difference was seen in the pattern of correlation between specific and general medication beliefs. As with previous data sets *General-Overuse* and *General-Harm* beliefs were significantly correlated (rho = 0.44; n=88; p<0.001). However, in contrast to earlier findings, *Specific-Concerns* were not significantly correlated with *General-Harm* or *General-Overuse* beliefs. There was a weak negative correlation between *Specific Necessity* and *General-Overuse* beliefs which did not reach significance at the 0.05 level (rho = 0.21; n=88; p<0.06). As in previous data sets *Specific Necessity* beliefs were weakly positively correlated with the number of prescribed medicines (rho= 0.22; n=88; p<0.05).

The relationship between demographic variables and BMQ-Specific factors was similar to previous data sets with no significant difference in scores according to age, sex or educational experience. Similarly *General-Overuse* and *General-Harm* scores were positively correlated with age (rho=0.3; n=88; p<0.01and rho=0.26; n=88; p<0.05). In contrast to all other data sets studied to date, significant gender differences were noted in *General-Overuse* scores with women attaining significantly higher mean scores that men (12.7 vs 11.4 t = -2.6; df = 8.6; p<0.05). No gender related differences were seen in any other BMQ-scores or in reported experience of side-effects.

9.4.3 Discussion

This study provides additional evidence in support of a coherent interaction between experience, attribution and individual BMQ dimensions. Consistent with self-regulatory theory, patients who reported having experienced side-effects associated with their current medication were much more likely to be concerned about current disruption and future harm and dependence (*Specific-Concerns*). However, this relationship was limited to

experience with current prescribed medication and was not extrapolated from experiences in the past. An interesting finding was that, although a similar distribution of beliefs about medicines in general was found among oncology patients and patients from other diagnostic groups, these did not influence *Specific-Concerns* in the oncology sample. One interpretation of this finding is that in the oncology group concerns arise from beliefs about a class of medicines (anti-cancer drugs) which are distinguished from medicines in general. In this case prototypic beliefs about anti-cancer drugs may have a stronger influence on beliefs about prescribed medication than more general beliefs about medicines as a whole. This explanatory hypothesis is supported by data from the asthma clinic sample (n=78), described in Section 8.3 in which beliefs about steroids (a specific class of drugs included as a component of the asthma regimen) had a much stronger effect on beliefs about the prescribed regimen than beliefs about medicines in general. This issue should be investigated in more detail. For example semantic differential techniques could be used to assess the degree to which people differentially attribute certain properties (e.g. long-term adverse effects, dependence, disruption, worry) to particular classes of drugs (e.g. anti-cancer medication vs. aspirin, vs. insulin etc.).

In the main, this study of oncology patients confirms previous findings in other illness groups that demographic factors do not influence beliefs about specific prescribed medication, but may be weakly related to more general medication beliefs. The observation that women had significantly higher scores on the *General-Overuse* dimension, conflicts with previous findings and cannot easily be explained. Further work is necessary to determine whether this is an anomaly.

9.5 The effect of illness cognitions on medication beliefs

Recent research on illness perceptions has found congruent associations between the five components of illness representation (Petrie et al. 1996; Weinman et al. 1996). For example, in Petrie and colleagues' prospective study of first time myocardial infarction patients, those who considered their heart condition to be of long duration, perceived it to have more severe personal consequences and were less likely to believe that it could be controlled or cured. These parameters might also influence the perception of prescribed medication. The present study examined associations between medication beliefs and these aspects of illness cognition: the five components of illness representation identified by Leventhal and beliefs about control over illness. This was an exploratory study which set out to examine correlations between illness perceptions, beliefs about control over

illness and beliefs about specific and general medication. The effect of reported duration of the patients' current illness on their medication beliefs was also examined.

9.5.1 Method

Participants

The asthma (n=78), diabetic (n=99) and renal (n=47) samples described in Chapter 6.3.1. Owing to limitations on the number of questionnaire items which could be administered to the illness groups, the IPQ had only been given to the above three samples. In particular we aimed to limit the number of items for those pateitns who were acutely ill in hospital. Thus the cardiac and general medical inpatients did not complete the IPQ. The number of items which could be administered to the psychiatric sample was limited by the fact that they were already taking part in an audit questionnaire. Thus the asthma, diabetic and renal groups completed the IPQ were chosen for inclusion on this basis.

Measures

- The Beliefs about Medicines Questionnaire (BMQ) (in Section 7.2.1).
- The Illness Perception Questionnaire (IPQ) (Weinman et al, 1996- see Section 6.4.1)
- Beliefs about control over illness as described in Section 6.4.2.
- Duration of illness: Estimates of the duration of illness were obtained by asking the patient how long the current illness had lasted.

Statistical techniques

- Relations between illness perceptions, control beliefs, duration of illness and medication beliefs were investigated using Spearman correlation.

Procedure

The data collection procedure is described in Section 6.5.

9.5.2 Results

Spearman correlations between BMQ factor scores, the five components of illness representation, central beliefs are shown in Table 9.7. Although certain correlations between medication and illness beliefs were significant, the relationships were inconsistent. Despite, this mixed picture several trends emerged. Interactions were more extensive in the asthma and diabetic samples than in the renal group. Associations between medication

beliefs and the 5-components of illness representation and control over illness beliefs will be considered in turn.

Table 9.7 Spearman correlations between BMQ factors and illness and control beliefs for three diagnostic groups: asthma (n=78), diabetes (n=99) and renal (n=47). Data in columns relates to asthma, diabetic and dialysis samples in order.

	Specific Necessity	Specific-Concerns	General-Harm	General-Overuse
Specific-Concerns	-0.20 .28* .18			
General-Harm	-.04 -.18 .23	.13 .45** .45**		
General-Overuse	-.26* -.10 .08	.04 .08 .59**	.29* .09 .40**	
IPQ Identity	.24* .28* .18	.28* .05 .38**	.13 .09 .20	.07 .05 .25
Number of causal Attributions	.00 -.20 .04	.15 .19 .47**	.11 .18 .18	.24* .14 .17
IPQ Timeline	.49** .41** .21	.19 -.25* .03	-.16 -.12 -.08	-.20 -.04 .08
IPQ Consequences	-.04 .30** .06	-.13 .26* .40**	-.03 .09 -.03	-.10 .19 .29
IPQ Control	.07 .18 -.06	.20 -.26* .06	.18 -.32** .22	.07 -.24* -.02
Control Over Illness Beliefs	.-.04 - -.07	-.26* - -.11	-0.1 - -.26	.09 - .08
Duration of) illness (years	.14 .44** .27	.18 -.13 .08	-.11 -.14 -.03	-.10 .14 .25

Identity Patients who endorsed a larger number of symptoms as being part of their illness had stronger beliefs in the necessity of their medication but this effects was limited to the asthma and diabetic groups. The *Identity* dimension was also positively correlated with *Specific-Concerns* in two samples . Asthma and renal patients who held strong *Identity* beliefs also had stronger concerns about prescribed medication. In contrast, to beliefs about

prescribed medicines, *Identity* scores were not correlated with beliefs about medicines in general.

Causal attributions The number of causal attributions made by patients was generally not strongly related to medication representation. An interesting exception was that in the renal sample, the number of causal attributions was positively correlated with Specific-Concerns.

Individual causal beliefs Spearman correlations between individual causal beliefs and BMQ scales are shown in Table 9.8. The relationship between beliefs about individual causal factors and representations of specific and general medication were particularly salient for diabetic patients. Those who endorsed other people, stress, diet, pollution of the environment and personal behaviour as causal factors were less likely to perceived their medication as necessary for maintaining health. The relationship between causal beliefs and *Specific-Concerns* was interesting. Those who attributed the cause of their illness to chance, other people, pollution of the environment, or their own behaviour had stronger concerns about their prescribed medicines. In the renal sample this relationship was extended to include attributions of viral or germ related causes. In this sample this attribution was also linked to a more negative view of medicines in general as evidenced by higher scores on the *General-Overuse* and *General-Harm* dimensions.

Timeline Views about the chronicity of illness were associated with medication beliefs. Asthmatic and diabetic patients who expected their condition to last a long time had stronger beliefs about the necessity of their prescribed medication. Diabetic patients who thought that their illness would be short-lived had fewer concerns about the long-term effects or risks of dependent (lower Specific-Concerns scores).

Consequences Diabetics who attributed more severe personal consequences to their illness had stronger *Specific Necessity* beliefs. These patients also tended to be more concerned about the perceived adverse effects of their medication, and this relationship was also found in the renal group. In the asthma group, patients with stronger beliefs in the potential for control or cure had slightly fewer concerns about prescribed medication and tended to have more positive views about medication in general.

Table 9.8 Spearman correlations between BMQ factors and Causal beliefs for three diagnostic groups: asthma (n=78); diabetes (n=99) and renal (n=47). (Data in columns relates to asthma, diabetic and dialysis samples in order).

	Specific-Necesity	Specific-Concerns	General-Harm	General-Overuse
Chance	.18	.03	.16	-.07
	-.05	.23*	.10	-.10
	.11	.15	.00	-.07
Other people	-.10	-.10	.01	.16
	-.32**	.29**	.14	.01
	-.10	.36*	.16	.23
Inherited	-.05	-.01	-.17	.09
	-.07	-.07	.20	.13
	.00	-.10	-.20	-.05
Stress	.04	.08	-.06	.07
	-.21*	.19	.16	.13
	.15	.16	-.09	.27
Diet	-.04	.06	.12	.00
	-.42**	.16	.10	.09
	.15	.09	-.09	.20
Pollution of environment	.07	.24*	.03	.16
	-.25*	.21*	.16	.03
	.03	.17	.05	.29
Own behaviour	-.16	-.08	.03	.01
	-.21*	.24*	.25*	-.11
	.14	-.26	-.27	.15
germ or virus	-.03	.04	.08	-.04
	.14	.07	.11	.19
	.17	.45**	.40**	.35*

Control/curability beliefs were not strongly related to medication beliefs. Statistically significant correlations between IPQ-Control-Cure and BMQ scales were obtained in only one sample. Diabetic pateitns who perceived low potential curability control had stronger concerns about prescribed medication.

Perceived control over illness Few relations were found between perceived control over recovery and medication beliefs. The one exception was that a weak, but statistically significant, negative correlation between Perceived Control and *Specific-Concerns* was observed in the asthma sample, indicating that those with external control beliefs, were slightly more likely to be concerned about their medication.

Duration of illness Significant correlations between reported duration of illness and medication beliefs were noted in the diabetic sample but not in the asthma or dialysis sample.

9.5.3 Discussion

This exploratory study is one of the first to link the five components of illness representations with the core dimensions of medication beliefs. It is immediately striking that, although illness and medication beliefs were related, there were variations in the pattern of correlations across the three diagnostic groups. In particular illness and medication beliefs were more closely associated in the asthma and diabetic samples than in the renal dialysis sample. This is clearly illustrated by the finding that beliefs about the nature and severity of symptoms attributed to the illness (*Identity*) and a more chronic view of the illness (*Timeline*) correlated with *Specific Necessity* beliefs in the asthma and diabetic samples but not in the renal group.

The explanation for the finding might be found in the features of illness and treatment which are characteristic of the respective conditions. In asthma and diabetes, medication is the mainstay of treatment. In contrast, dialysis patients are subjected to a tri-partite regime of haemodialysis, medication and diet/fluid restrictions. For these patients dialysis is the primary treatment and the main purpose of diet fluid restrictions and medication is on maintaining body electrolytes (Will and Johnson, 1994). The primary role of dialysis is reinforced to the patient by the knowledge that they will die if they miss even a few successive dialysis sessions. In such circumstances it is perhaps unsurprising that views about illness *identity* and *timeline* beliefs are not closely associated with beliefs about the medication. For dialysis patients, perceptions of illness might be more closely associated with representations of haemodialysis then other components of the treatment regimen.

More negative views about personal (*Specific-Concerns*) and general medication (*General-Harm* and *General-Overuse*) tended to be associated with more negative views about illness. Diabetic and asthma patients who perceived their illness to have more severe personal consequences were more likely to worry about the harmful effects of their medication. Similarly strong illness *Identity* beliefs, a larger number of causal attributions and a low perception of illness controllability (IPQ *Cure/Control*) were all associated with stronger *Specific-Concerns*. Likewise, asthma patients who believed that external factors had greater control over their illness than factors under internal, personal control were slightly

more inclined to worry about the perceived adverse effects of their medication. The negative correlation between *Timeline* and *Specific-Concerns* observed in the diabetic sample appears to be counter-intuitive. One might expect the view of a long term illness to be associated with increased concerns about the potential for dependence and long-term effects. However, correlation was weak and limited to this sample and further work is necessary to ascertain whether this finding is meaningful.

The attribution of symptomatic benefit to medication was positively related to beliefs in its necessity in all three samples. This is consistent with self-regulatory theory which suggests that somatic experience exerts an important influence on illness-related cognitions. The identity component, which measures the perceived experience of symptoms associated the illness, was also correlated with beliefs about necessity, adding further support to the notion that beliefs about the necessity of prescribed medication are influenced by symptoms which are associated with the illness and whether medication is thought to alleviate them.

It is also interesting that perceptions of the likely duration of illness (*Timeline* scores) were more strongly associated with medication beliefs than the actual duration of the disease. Statistically significant correlation between duration of illness and medication beliefs were found in only one sample. Diabetic patients who reported a longer duration of illness had stronger beliefs in the necessity of their prescribed medication ($rho=0.44$; $n=99$; $p<0.01$). However, the magnitude of the association was greatly reduced when controlling for timeline beliefs ($rho=0.24$; $n=99$; $p<0.05$).

9.6 Culture and medication beliefs

Culture is the collective noun for the conventional patterns of thought and behaviour, including values beliefs and rules of conduct, which distinguish a particular social group and that are learned rather than inherited (Tattersall, 1995). Culture may thus have a powerful influence on many aspects of peoples' lives including those relating to health (Helman, 1990). The emergence of culture as a key concept in social research owes much to anthropologists who have observed and documented beliefs and behaviours which appear to be characteristic of particular cultural groups. The work of Kleinman has highlighted the potential role of culture as a determinant of health beliefs. In particular, he asserts that peoples' 'explanatory models' of illness may be characteristic of a particular culture (Kleinman, 1980; Kleinman et al. 1978).

Explanatory models are lay theories about the causes and mechanisms of disease and illness which inform beliefs about strategies to promote, maintain or restore health. In Kleinman's view explanatory models are held by individuals but are strongly influenced by culture. They may pertain to diseases which are recognised by "western medicine" such as hypertension (Heurtin-Roberts, 1992) Aids (Farmer, 1994; Farmer and Good, 1991) and the common cold (Kim and Lagakos, 1994) or to maladies which appear to be unique to the culture in question and which have no biomedical equivalent. The latter have been called folk illnesses and Patcher, provides several examples in a review of this topic (1994). He also points out that physicians and other health care providers constitute a "cultural group" on account of their specialised training, language, and codes of ethics and behaviour. He refers to this as the "culture of biomedicine".

Certain illness beliefs may be characteristic of particular cultures (Sissons-Joshi, 1995). Futhermore, it is suggested that culturally-specific explanatory models of illness might influence health related behaviours (Hilbrands et al. 1995; Pachter et al. 1992; Pachter, 1994; AmaraSingham, 1980). Interest in the role of culture in health beliefs and behaviour has increased among health psychologists. In a recent paper, Leventhal and colleagues (1997) suggest that many culturally bound explanatory models may have a common cognitive basis. For example, notions of "hot- cold" seem to be common to a variety of explanatory models of illness in several cultures.

Although there is some evidence that notions of modern medicines may be incorporated into the explanatory models adopted by particular cultural groups (Morgan, 1983; Robbins and Kirmayer, 1991; Kruse et al. 1994), the effect of culture on medication representations has yet to be investigated quantitatively. The present study set out to explore interactions between culture and two aspects of medication beliefs: representations of medicines in general and beliefs about personal sensitivity to the potential adverse effects of medicines. It addressed the question of whether people from different cultural groups had quantitatively different views about the nature and use of medication. Two cultural groups were chosen for comparison . The first was based on a measure of "cultural background" according to whether participants classified their cultural background as Asian or European. The study also addressed the impact of "professional culture" on medication beliefs by investigating whether students' beliefs about medication differed according to the university course they had chosen. This follows the notion that professional groups constitute cultures. The aims of this study were therefore:

1. To investigate whether representations of medicines in general and beliefs about personal sensitivity to the potential adverse effects of medicines, differed according to cultural origin (Asian vs. European).
2. To determine whether representations of medicines in general and beliefs about personal sensitivity to the potential adverse effects of medicines, differed according to course attended (pharmacy vs. mechanical engineering, vs. accounting and finance vs. social policy vs. humanities).

9.6.1 Method

Overview An exploratory cross-sectional study in which undergraduate students at Brighton University UK, completed questionnaires assessing beliefs about medicines in general together with demographic details and past and current experience of taking medication. Five university courses were selected in an attempt to represent a broad range of chosen topics of study. Topic of study was considered to be a proxy measure of 'professional culture'. The courses were: Pharmacy, Engineering, Accounting and Finance, Social Policy and Administration, Humanities. The aim was to include a sample of students from the academic year of each course.

Participants

University undergraduate student sample (n=600) described in Section 6.3.2.1.

Measures

- Beliefs about medicines in general assessed using the *General-Harm* and *General-Overuse* scales of the Beliefs about Medicines Questionnaire (BMQ) described in Section 7.2.1.

In order to investigate beliefs about the potential benefits of medicines four statements, shown in Table 9.9, pertaining to the possible benefits of medication were added to the BMQ-General. Responses were scored on a 5-point Likert scale where 1=strongly disagree and 5 = strongly agree. Although this scale has not yet been fully evaluated or validated in relation to the BMQ it is here, for convenience, labelled as ***General-Benefit***.

Table 9.9 Statements assessing beliefs about the benefits of medicines in general (General-Benefit)

- Medicines help many people to live better lives
- In the future medicines will be developed to cure most diseases
- In most cases the benefits of medicines outweigh the risks.
- Medicines help many people to live longer

Cronbach alpha = 0.54: n=588 (12 subjects had missing data)

- The Sensitive Soma scale was used to assess beliefs about personal sensitivity to the potential adverse effects of medication as detailed in Section 6.4.7.
- Past and present experience of taking medication was assessed by responses to the following questions:

  Are you currently taking prescribed medication (yes/No)
  Have you ever received a prescribed medicine (yes/no)

- Participants were asked to select their cultural origin by from the following list: Afro Caribbean, African, Asian, European, Other.
- Participant demographic details: age, gender, course attended, year of study.

Procedure

Permission to invite students to take part in the study was obtained from relevant members of academic staff (e.g. course leaders). Students were approached at the start of a core-lecture and invited to take part in the study by a third year undergraduate pharmacy student. Those who agreed were then given five minutes to complete the study questionnaire before the lecture began. Completed questionnaires were collected by the student. In most courses students were split into two main groups for ease of teaching and we aimed to approach at least one group in each year. This was achieved for each year, but about two thirds of students in year 3 of the Accounting and Finance were not eligible for inclusion in the study as they were absent on placement during the recruitment period.

Analysis

The analysis was conducted in four stages:

1. The interaction between professional culture (course attended) and medication beliefs was investigated in the total data set (n=600), using analysis of variance with post-hoc Tukey's HSD.

2. The effect of cultural background on beliefs was evaluated in a sample of Asian and European students matched according to course attended, age and gender. Independent sample t-tests were used to investigate differences in BMQ-General and Sensitive Soma scale scores using cultural background as the independent variable.
3. Further analyses were conducted to assess the extent to which interactions between beliefs and cultural background were independent of past and present experience of taking prescribed medicines. Partial correlations between cultural background (Asian vs. European) and scores on the BMQ and SS scales, were examined controlling for past and present experience with prescribed medication.
4. Finally, the combined effect on medication beliefs of cultural background, professional culture and experience with medication was examined within the matched group (n = 160), by linear regression of the culture and experience variables against each of the BMQ and SS scales.

9.6.2 Results

The demographic characteristics of the sample are shown in Table 6.4 in the Methodology chapter. The results of the statistical evaluation of medication beliefs according to cultural background are described below.

The effect of "professional culture" on medication beliefs

The results of ANOVA with post-hoc Tukey's HSD shown in Table 9.10 and graphically in Figure 9.4, indicate that beliefs about medicines in general were significantly influenced by the course attended. A clear pattern emerged with a distinct ordering effect. The pharmacy students were significantly more likely to have strong beliefs in the overall benefits of medication and significantly less likely to believe that medicines in general are harmful and overused by doctors than all other groups. Moreover, this group were significantly less likely to perceive themselves as being sensitive to the potential adverse effects of prescribed medication as indicated by lower group mean scores on the Sensitive Soma scale. Moreover, positive views about medication in general increased in the following order: humanities, social policy, accountancy, mechanical engineering, pharmacy. A similar ordering effect was noted for Sensitive Soma scores with pharmacy students having lower mean scores than all other groups and significantly lower mean scores than the social policy and humanities groups (F prob<0.0001).

Table 9.10 Scale means and standard deviations for BMQ -General and Sensitive Soma scales for five undergraduates of five "cultural groups"

Scale		Pharmacy n=154	Humanities n=75	Mechanical Engineering n=120	Accounting & finance n=133	Social policy & administration n=111	F	p
General-Harm	Mean	8.5	10.2_a	10.2_a	10.4_a	10.0_a	15.8	<0.0
	SD	2..3	2.2	2.4	2.4	2.1		
General-Overuse	Mean	$13.1_{b,c}$	14.1_c	12.9_b	13.0_b	$13.3_{b,c}$	2.8	<0.0
	SD	2.7	2.8	2.3	2.5	2.5		
General-Benefit	Mean	15.8_d	13.8_e	14.8_f	$14.6_{e,f}$	$14.4_{e,f}$	15.2	<0.0
	SD	1.9	1.8	2.4	2.2	2.0		
Sensitive Soma	Mean	11.0_h	12.8_g	$11.3_{h,i}$	$11.2_{h,i}$	$12.0_{g,i}$	6.3	<0.0
	SD	3.2	3.4	3.4	3.1	3.4		

Note: Means sharing the same subscript are not significantly different by Tukey's HSD test (p>0.05).

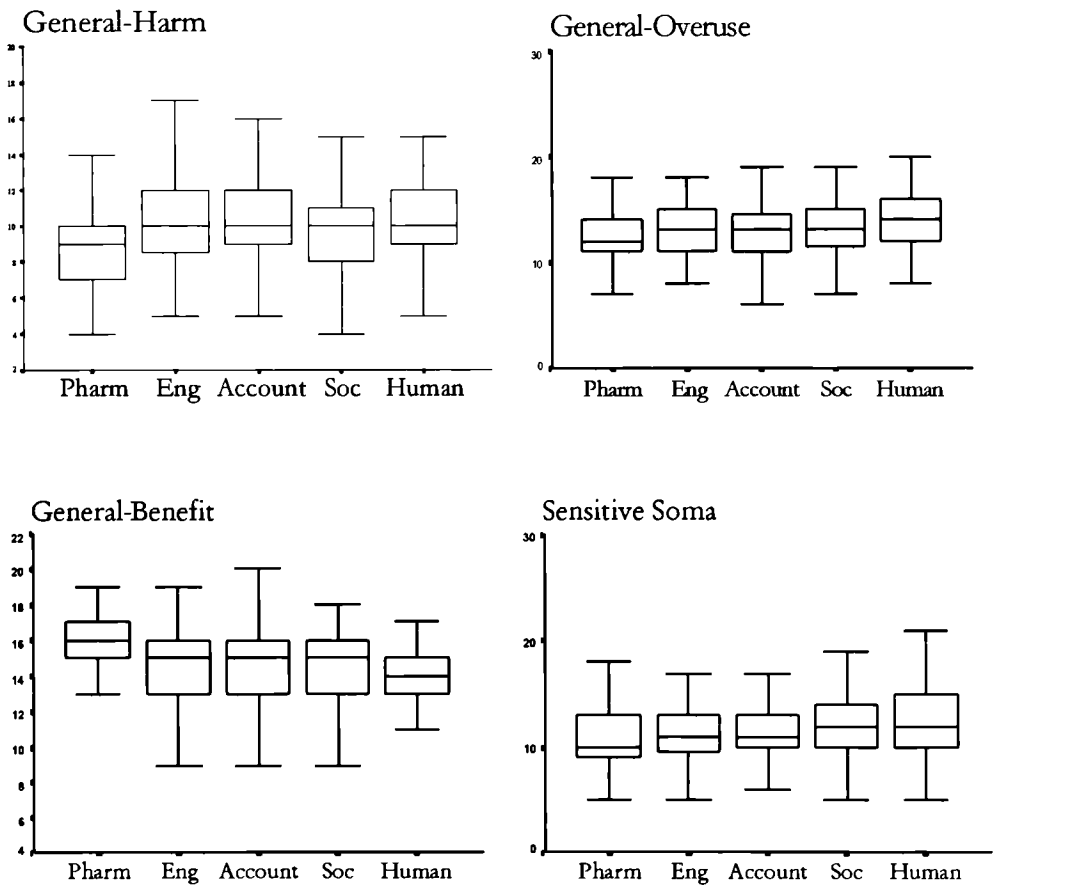


Figure 9.4 Box-plot of medication beliefs scores by course

The effect of cultural background on medication beliefs

Cultural background had a clear influence on medication beliefs. Asian participants had a more negative view about medicines in general than those who had indicated a European cultural background. Table 9.11 shows that the Asian cultural group had significantly higher mean scores on the *General-Harm* and *General-Overuse* scales indicating stronger beliefs in the notion that medicines in general are harmful, addictive poisons which should not be taken for long periods of time and that they are overused by doctors. The Asian group also had significantly lower scores on the General- Benefit scale indicating less agreement with the idea that medicines in general have primarily beneficial effects upon health.

Table 9.11 Mean (SD) scores on beliefs about medicines scales in a sample of Asian and European undergraduate students matched for age, gender and course attended

Variable	Asian (n=80)	European (n=80)	t value	P value
General-Harm	10.28 (21)	9.39 (2.6)	2.34	<0.05
General Overuse	13.52 (2.3)	12.40 (2.5)	2.91	<0.01
General-Benefit	14.57 (2.2	15.66 (2.0)	-3.29	<0.01
Sensitive Soma	11.44 (3.2)	11.05 (3.2)	0.75	0.45

The influence of past and present experience of medication taking on cultural effects

Significantly fewer Asian than European students reported first hand experience with prescribed medication in the past (34% vs. 56%; Chi square = 8.2; $p < 0.01$) and present (15% vs. 27% Chi square = 3.7; $p < 0.05$). However, partial correlations between cultural background and BMQ and SS scales, controlling for past and present experience showed that differences in belief scores among cultural groups could not simply be attributed to differences in relative experience of medication (see Table 9.12 below).

Table 9.12 Partial correlations between cultural background (Asian vs. European) and medication beliefs controlling for past and present experience with prescribed medication

	General-Harm	General-Overuse	General-Benefit	Sensitive Soma
Cultural Background (Asian vs European)	-.23**	-.24**	.24**	-.06
Cultural Background -controlling for past and present experience with prescribed medication	-.16*.	-.20*	27**	-.02

Evaluation of the combined effects of cultural background, professional culture and experience of prescribed medication

The results of linear regression analysis within the matched data set (n=160), shown in Table 9.13, demonstrate that cultural background had a small but statistically significant influence on beliefs about medicines in general but not beliefs about personal sensitivity to the potential adverse effects of medication (Sensitive Soma scores). Moreover, experience with medication did not add significantly to the variance in belief dimensions, explained by cultural background and professional culture (course attended).

Table 9.13 Multiple linear regression analyses of BMQ-general and Sensitive Soma scale scores

	Variable	B	SE B	Beta	T	Sig T	R^2
General-Harm	Course	-.98	.35	-.21	-2.77	.01	.10
	Culture	.54	.12	.33	4.36	.00	.15
General-Overuse	Culture	-1.15	.38	-.23	-3.02	.00	.05
	Course	.28	.13	.17	2.15	.03	.08
General-Benefit	Culture	1.07	.32	.25	3.33	.00	.06
	Course	-.38	.11	-.26	-3.42	.00	.06
Sensitive-Soma	None of the entered variables were retained within the equation at the .05 significance level						

Variables included in the analysis:

- Culture = cultural background; Asian vs. European
- Course = Course attended (pharmacy, mechanical engineering, finance and accounting, social policy and administration, and humanities)
- Past experience of taking prescribed medication
- Currently taking prescribed medication

Variables shown in the table those retained after stepwise removal and entry at the .05 significance level.

9.6.3 Discussion

This study is one of the first to quantify the effect of cultural factors on medication beliefs. The findings show that both professional culture and cultural background were determinants of beliefs about medicines and, in the case of professional culture, beliefs about personal sensitivity to the adverse effects of medication.

Cultural background influenced beliefs about medicines as a whole but not perceptions of personal susceptibility to their adverse effects. The selectivity of this effect reinforces the view that differences in orientation to medication, are mediated by the influence of culture

on beliefs about medicines rather than by fears about personal sensitivity or past experience of adverse effects.

It is relevant that Asian respondents had significantly less experience with prescribed medication than their European counterparts. In the total student group (n=600), current and previous experience of taking medication was associated with a more positive orientation to medicines in general. Similar findings have been reported in the literature relating to attitudes towards benzodiazepine tranquillisers, with users reporting more favourable attitudes towards these drugs than no-users (Mansbridge and Fisher, 1984; Clinthorne, 1986). However, the clear differences in beliefs about medicines between Asian and European participants could not be accounted for by differential experience of taking medication. This study corroborates an earlier qualitative study in which differences in attitudes to the treatment of hypertension were noted between Afro-Caribbean and Anglo-Saxon Londoners (Morgan and Watkins, 1988).

In this study I did not distinguish between South-East Asian (eg Vietnam Taiwan and Indian or Pakistani Asian. Our notion of Asian culture, thus encompasses a range of separate cultures and explanatory systems. However, both Asian cultures are associated with explanatory models and attitudes to illness which are alien to Western biomedicine and which may predispose against it (Khajuria and Thomas, 1992; Uba, 1992). This simple, exploratory study sheds little light on why Asian students had a more negative orientation to medicines. However, it is interesting that the traditional Hindu Ayuvedic system of medicine emphasises herbal remedies (Schechtman and Gordon, 1994; Sissons-Joshi, 1995) and beliefs that modern pharmaceutical carry the risk of dependence has been noted in rural communities in Pakistan (Hunte and Sultana, 1993). It noteworthy that the majority of respondents who gave their cultural origin as Asian would have been naturalised UK residents. It is therefore likely that culturally related attitudes have been passed on from parents or grandparents. Culturally-related differences in medication beliefs may be even stronger for older members of the Asian culture.

It was quite surprising that such clear differences existed between students on the basis of their chosen courses (here taken as a marker for future professional activity). In the case of pharmacy students, positive orientation towards medicines might have influenced their choice of degree. However, the same could not be said for mechanical engineers (few of whom would admit to being "failed pharmacists"), who had more positive views about medicines than all other groups - except pharmacy. This raised a 'nature-nurture' question.

Did pharmacy students start out with a more positive view of medicines (nature) or were their attitudes 'shaped' by the course (nurture)? If the course shaped these attitudes one would expect to see changes between first and third year students. This was investigated by using a 3 (year) by 5 (course) ANOVA. This showed no significant effect of year of course and no significant interaction between course and year suggesting that students' attitudes were formed before they arrived at University. This was confirmed by a further ANOVA of year of study and medication beliefs which showed no significant effect of year of study on medication beliefs. The generalisability of this finding is limited by the cross-sectional nature of the data. One needs to follow students from day 1 of the course to confirm these explanations. However, the preliminary findings reported here suggest that the prototypic views about medication may be formed fairly early on, possibly during adolescence and this could be addressed in future research.

The fact that pharmacy students had a quantitatively different view of medication then their colleagues, at such an early stage in their career, may have implications for patient-pharmacist communication. If differences in views about medication are maintained once the student is qualified and practising pharmacy in a health care setting, then they could become a barrier to effective communication between pharmacist and patient. If the pharmacist assumes that the patient shares their own positive orientation towards medicines then there may be little incentive to elicit the patient's personal concerns about prescribed medication. The earlier finding that less experience of formal education was associated with a more negative view of medicines in general (reported in Study 7.1) suggests that discrepancies between "professional" and "lay" views about medicines may be even more marked than those observed in this study.

The generalisability of the findings to professional-lay differences in the real world is, of course, limited by the use of students' choice of course as a marker for "professional culture". Further work is needed to establish whether this pattern of differences is observed between health care professionals and the lay public and between individual professions (e.g. pharmacy vs. medicine vs. nursing) and to clarify the implications for service delivery. Another outstanding question relates to the mechanism of interaction between choice of course and medication beliefs. Why are scientists (pharmacists and mechanical engineers) more positively orientated towards to medication than their colleagues working in finance, policy of other areas? To what extent are views about medication linked with beliefs about science and technology? Moreover, how does this influence interaction with the medical establishment if it is perceived as having a technical-

scientific orientation? Further work is now justified to investigate this issues in more detail. In particular to discover whether cultural influences on orientation to medicines as a whole influence views about medication prescribed for particular illnesses and medicine taking and to clarify the implications for shared-decision-making and provision of information about medication.

CHAPTER 10
Summary of findings and general discussion

The empirical work which underpins this thesis used quantitative research methodologies to investigate medication beliefs in a sample of patients drawn from six chronic illness groups: asthma, diabetes, end-stage renal failure, chronic heart disease, psychiatric outpatients patients and a sample of general medical in-patients. Data collected from these samples provides the core data for the subsequent investigation of the structure, effects and determinants of medication beliefs. In some studies these core data were augmented by data collected from additional samples including oncology patients, undergraduate students and people seeking care from community pharmacies or complementary therapists.

10.1 The nature of medication representations

10.1.1 Are cognitive representations of specific and general medication structured around coherent themes?

Previous studies of medication beliefs had identified a fairly large number of beliefs about medication. (Conrad, 1985; Morgan and Watkins, 1988; Lorish et al. 1990; Fallsberg, 1991; Donovan and Blake, 1992; Echabe et al. 1992; Woller et al. 1993; Britten, 1994). Initial studies described in Chapter 7 were concerned with identifying the core dimension underlying medication beliefs. A series of Principal Components Analyses (PCA) revealed that beliefs about medication prescribed for the patient's illness (Specific) and more general beliefs about medicines as a whole (General) were structured around four factors or dimensions.

PCA revealed a clear distinction between Specific and General medication beliefs. The first dimension underlying beliefs about prescribed medication related to the perceived *necessity* of medication for maintaining health (*Specific-Necessity*). The second factor comprised items relating to *concerns* about the adverse consequences of medication based on beliefs about the potential for dependence or harmful long-term effects and that medication taking is disruptive (*Specific-Concerns*).

Beliefs about medicines in general also resolved into two factors. The first comprised items expressing beliefs about the way in which medicines are used by doctors. The essence of this factor, labelled *General-Overuse* was the notion that medicines are over-prescribed by doctors who place too much trust in them. The second factor, labelled *General-Harm* related to the intrinsic properties of medicines and included representations of medication as harmful, addictive, poisons grouped with the belief that people who take medicines should stop their treatment every now and again.

These factors were used to form the Beliefs about Medicines Questionnaire (BMQ) which proved to have acceptable psychometric properties within the study sample. The BMQ factors were fairly stable across a range of illness groups and in, the case of *General-Overuse* beliefs, healthy undergraduate students. The identification of simple stable factors is only of value if the factors are meaningful. So what meaning could be assigned to the BMQ factors? A key issue here was whether the factors were the core components of specific and general representations of medication analogous to the five components of illness representation identified by Leventhal and colleagues (1980). Accepting this premise would imply that ideas about medication are predominantly structured around *necessity*, *concerns* (for prescribed medication) and *harm* and *overuse* (for medicines in general). An alternative possibility is that the BMQ factors are some, but not all, of the underlying dimensions of medication beliefs. There are, however, important differences between the medication belief constructs identified in this study and Leventhal's five components of illness representation arising from the way in which they were derived.

PCA and factor analytic techniques, used in the present study to identify core medication beleifs, are designed to identify underlying factors which account for the observed correlation between items. The aim is to obtain simple factor structures which are stable across data sets. This has the obvious advantage of reducing complex variables to core themes upon which to focus further study. However, the attainment of simple stable structure often results in the loss of items which do not load on the underlying factors or which have non-linear relationships with the other items. Simplicity of structure is obtained at the cost of complexity of information. In contrast, the multidimensional scaling (MDS) techniques used to identify the core dimensions of illness representation (Leventhal and Nerenz, 1985) are designed to identify clusters within data sets. The emphasis is on grouping by proximity rather than simplification to common latent factors (Croyle and Barger, 1993).

The cost of simplification is illustrated in the General beliefs data set by the loss of several interesting items such as "*Medicines are a necessary evil*", "*It is better to do without medicines*", "*Stronger medicines are more effective than older ones*", "*Stronger medicines are more dangerous than weaker ones*". It is interesting that the *General-Harm* factor was slightly unstable in the general medical sample and had low internal consistency in others. This indicates that peoples' representations of medicines are complex and varied and are not easily "condensed" into simple factors. A further point of interest was that a coherent "General-Benefit" dimension did not arise which is consistent with the observation from interview studies that people often appear to take the benefits of "modern medicines" for granted (Conrad, 1985; Morgan and Watkins, 1988; Britten, 1994). However, the failure to identify a benefit dimension might simply reflect the fact that the items selected for initial analysis were inappropriate. A broader range of beliefs items might have facilitated the emergence of a benefit dimension.

Given this limitation of PCA, why was this technique chosen? The answer to this reasonable question is that the benefits of simplicity were perceived to outweigh the costs. The literature review identified a fairly complex array of lay beliefs but very few studies had systematically assessed quantitative relationships between medication beliefs and other variables. In contrast to the extensive literature suggesting the salience of illness cognition to health behaviour, there was relatively little evidence to support the utility of medication beliefs (e.g. Eagleton et al, 1993). Thus it was felt that an initial priority was to investigate the utility of medication beliefs in health-related cognition and behaviour rather than a full description of the components of medication cognitions.

So how do the BMQ factors inform our understanding of the cognitive organisation of medication beliefs? To answer this question we need to distinguish between Specific and General medication beliefs. Most of the beliefs relating to prescribed medication which have been described in the literature can be summarised as notions of necessity or concerns about negative effects. Although these themes are not all inclusive, they are perhaps the core dimensions underpinning attitudes to prescribed medication. However, other Specific medication cognitions may also be salient. For example, ideas about *efficacy* and how one decides whether the medication is working properly are not represented by the BMQ factors. Efficacy cognitions might inform *necessity* beliefs and *concerns*. For example, the belief that a medicine is not working may be a source of Specific-Concerns if the patient perceives the medication to be necessary for maintaining their health.

Alternatively, the perception that the medication is not working might reduce beliefs in its necessity, particularly if the patient feels well. Thus efficacy beliefs may be thought of as core representations in their own right. An alternative view is that efficacy beliefs might be "secondary beliefs" which inform the core dimensions of *necessity* and *concerns*. (A similar concept is that beliefs about the *severity* of a disease might inform the *Consequences* component of illness representations). The fact that in the present study an "efficacy" item ("*My medicines are effective*") was not retained within the PCA may be consistent with the latter explanation, but further studies are necessary to confirm this.

The BMQ-General factors, are likely to be more limited in scope as they were derived from a sample of chronically ill patients with experience of medication. The *General-Harm* factor is particularly problematic. The internal consistency of this factor was low, even in some of the illness samples from which it was derived. Low internal consistency was also noted in the undergraduate student sample (Cronbach alpha=0.54; n=600) and among those seeking care from community pharmacies and complimentary practitioners (Cronbach alpha=0.55; n=139). As mentioned earlier, this suggests that peoples' tend to have fairly complex ideas about medicines as a whole which cannot easily be condensed into simple core factors relating to the intrinsic nature of medicines. In contrast, the *General-Overuse* factor was more stable having a higher internal consistency in both the undergraduate (Cronbach alpha=0.64; n=600) and community pharmacy/complimentary practitioner samples (Cronbach alpha=0.78; n=139). Further work is therefore needed to confirm the stability of the *General-Harm* factor structure.

At least one important belief identified in the literature was not represented in the BMQ-General. This is the idea that one can become "immune" or tolerant to the beneficial effects of medication is they are taken regularly (Fallsberg, 1991). This belief might be important . As a concern about prescribed medication, this might become a barrier to adherence. This notion was not included in the original items subjected to PCA. In studies where this belief has been noted it seems to arise in relation to specific classes of drugs: antibiotics and analgesics (Britten, 1994, Donovan & Blake, 1992, Fallsberg, 1991, Lorish et al, 1990). However, its omission from the study raises several issues. This would seem to be one of the salient medication beliefs which is absent from the BMQ as it does not relate to concepts of intrinsic harm (General-Harm) and is not specifically about overuse of medicines by doctors , although it is clearly related to this issue and might inform views about overuse.

The fact that the final BMQ factor structure does not include some of the beliefs about medication which described in the literature, suggests that these factors are not the only components of medication representation. However, they may represent the important dimensions of belief which inform attitudes to medication.

10.1.2 The distribution of medication beliefs

The face validity of the BMQ constructs justified further investigations of the distribution of these beliefs among chronically ill patients. Whereas beliefs about *General-Overuse*, *General-Harm* and *Specific-Concerns* were normally distributed, *Specific-Necessity* were heavily skewed towards the positive. The lack of variance in necessity beliefs is unsurprising given the study sample was limited to patients with severe illnesses, many of whom have been in treatment for some time. One might expect to find that such patients believed that their medication was necessary, after all, medication was a prominent part of their treatment regimen. Thus, the sample is in some ways self-selecting in that they were patients who had remained in treatment and who were therefore more likely to be perceive their medication as necessary. One of the problems with this is that the utility of the construct may be diminished because it does not differentiate between individuals. A greater variance in the *Specific-Necessity* dimension might have been obtained by the inclusion of other chronic illnesses where medication is prescribed as prophylaxis rather than treatment such as hypertension, or the treatment of chronic infectious diseases such as tuberculosis.

The next question addressed by the analysis was how medication beliefs were related to one another and whether this might reveal something of the way patients were thinking about medication. Although, they were conceptually distinct the BMQ factors were related in a fairly consistent way which seemed to suggest a logical interaction between beliefs. For example, those who saw medicines in general as intrinsically harmful (*General-Harm*) were more likely to believe that they are overused by doctors (*General-Overuse*). Similarly, negative views about medicines in generally were associated with stronger concerns about prescribed medication. Correlations between specific medication beliefs, suggested that, for a third of the total chronic illness sample strong beliefs in necessity coincided with strong concerns. These patients seemed to have a rather complex view of their prescribed medication in which high benefit was balanced by high cost. In an earlier qualitative study of medication beliefs, Fallsberg (1991), noted that some of her sample of Swedish asthma,

epilepsy and chronic pain patients held a similar "dualistic view" in which medicines were seen as a "necessary evil". The present finding confirms the relevance of this notion and quantifies its prevalence in a UK sample.

10.2 The effects of medication beliefs as correlates of medication adherence.

The *Specific-Concerns* construct contains items related to the long-term adverse effects of medication and its potential to cause dependence. Several qualitative studies have suggested that these beliefs might influence adherence (Morgan and Watkins, 1988; Donovan and Blake, 1992; Conrad, 1985). Additionally, in Woller and colleagues' (1993) study of German patients with asthma, beliefs about addiction contributed to the "threatening aspects" of steroids which were related to low adherence. The next step therefore was to investigate relations between medication beliefs and adherence. This was done in a series of analyses described in Chapter 8. To begin with, correlations between the four medication belief factors and reported adherence to medication were examined in each diagnostic group.

An interesting pattern of correlations emerged. Although correlations between reported adherence and BMQ-General scales were in the predicted direction, the coefficients were small and rarely reached statistical significance In contrast, beliefs about prescribed medication were significantly correlated with reported medication adherence in all but one of the illness samples. Patients with stronger beliefs in the necessity of their prescribed medication reported higher adherence rates and those with stronger concerns reported lower adherence rates.

Multiple linear regression analysis showed that age and medication beliefs accounted for 27% of the variance in reported medication adherence, with beliefs about prescribed medication contributing 13% to the total variance explained. It is interesting that people's views about the specific medication regimen prescribed for them were much more strongly related to adherence reports than were more general views about medicines as a whole. Moreover, the interplay between concerns and necessity beliefs implied a risk-benefit analysis and subsequent attempts to moderate the perceived potential for harm by taking less. It is also interesting to note that the association between medication beliefs and reported adherence was of a similar magnitude to that attributed to HBM variables in a previous study of medication adherence (Ried and Christensen, 1988).

Additionally two findings emerged from the analyses which merit further attention. First younger patients reported lower adherence. Second, no significant associations were found between medication beliefs and adherence in the psychiatric clinic sample. These findings will now be discussed in more detail.

10.2.1 Age and reported adherence to medication

The consistent finding that younger patients reported lower adherence is contrary to the commonly held view that older patients are less adherent (Griffith, 1990). However, earlier research examining the effect of age on adherence is inconclusive (Haynes et al. 1979) and the observed relationship between age and adherence reported here is consistent with more recent work showing that it is mistaken to regard older patients as a homogenous group of low adherers (Lorenc and Branthwaite, 1993).

Why are younger patients less adherent to medication? One possibility is that the finding is an artefact attributable to a greater willingness to report non-adherence. Although the context of adherence questions was controlled to encourage truthful reporting, it is not certain that this strategy was effective. However, a number of other recent studies have also found higher rates of adherence in older patients (Daniels et al. 1994; Sherbourne et al. 1992; DiMatteo et al. 1993; Frazier et al. 1994; Lorenc and Branthwaite, 1993). The explanation for this effect may lie in cognitive differences in the approach to illness associated with older age. There is evidence that older people tend to adopt a more cautious approach to the maintenance of health (Leventhal EA et al. 1993a; Cameron et al. 1993; Leventhal EA et al. 1993b). Consequently, once the patient has accepted the advised behaviours as necessary and valid, they tend to adhere to them more carefully and systematically (Leventhal EA and Crouch, in press). Elderly patients may thus be more averse to risk and less willing to act on their concerns by adopting the "risky" strategy of altering their medication (Leventhal et al. 1992b).

Other factors may also explain the link between older age and adherence. Brownlee-Duffeck and colleagues (1987) noted age related differences in illness cognition in a sample of insulin treated-diabetics. There were distinct differences in the type of cognitions which predicted adherence. Whereas the *barriers* dimension of the HBM predicted adherence in younger patients, perceived benefits were much more salient in the older group, suggesting that the priority assigned to particular cognitions may vary with age. This argument can be applied to specific medication beliefs. In the present study the relationship between

concerns and reported adherence was independent of age. Elders had similar concerns as their younger counterparts which were related to adherence in a similar way. However, it may be that other cognitions were more salient for elderly patients and resulted in an stronger effect on reported adherence.

Concerns about the risk of dependence and long term effects of medication may have a lower priority for elderly patients than other factors such as the perceived *vulnerability* to the adverse effects of omitting medication. Another possibility is that normative beliefs attain greater salience with advancing age. In support of this notion there is evidence that elders tend to have stronger beliefs in the powerful others dimension of the locus of control construct, perceiving doctors to have a high degree of control over their health (Lachman, 1986; Lumpkin, 1986). Elderly patients may therefore be more reluctant to depart from their doctors instructions. Furthermore, these cognitions might mitigate against the effect of other- as yet undefined adherence related cognition which are salient for younger adults.

Finally it is interesting to note that the tendency of older patients to be more "respectful" of their doctors may be a cohort effect specific to the current generation of elders rather than a true effect of age on illness-related cognitions. It is possible that the introduction of the NHS, with its paternalistic culture of health provision had a formative effect on health-related attitudes which is unique to the generation which experienced its inception.

10.2.2 Beliefs and adherence in the psychiatric clinic sample

The psychiatric out-patient sample provided a notable exception to the other illness samples studied in that no significant correlations were noted between medication beliefs and adherence. A clear reason for this apparent anomaly could not be found within the data. The lack of interaction could not be attributed to disruptions in cognitive processes linked to psychotic illness. The sample comprised roughly equal numbers of patients with neurotic and psychotic illness and the pattern of interactions was similar in both groups. Moreover, in both groups, correlations between specific and general medical beliefs were similar to those found in the other chronic illness samples studied with logical "common-sense" associations between beliefs (e.g. stronger beliefs that medicines are generally harmful substances which are overused by doctors tended to be associated, albeit fairly weakly, with greater concerns about prescribed medication).

Previous studies in which SCMs were applied to medication adherence in this area may help to interpret these findings. Although few in number these studies give a fairly clear indication of the types of cognition which might influence medication in this area. Cochran and Gitlin (1989) applied the Theory of Reasoned Action (TRA) to reported lithium adherence in patients with bipolar affective disorders. Although a modified version of the TRA explained 53% of reported adherence to lithium, patients' beliefs about taking lithium did not contribute directly to this. Rather, patients' attitudes and intentions towards medication and their reported behaviour were much more strongly influenced by the perceived views of significant others such as their family, friends and doctor than by their own beliefs about the treatment. Similarly, a recent study conducted in the USA found that positive attitudes to medication adherence were associated with social support and a broader array of daily activities (Draine and Solomon, 1994). Other studies suggest that patients' beliefs about the *severity* of relapse and their personal *susceptibility* to it are fairly strong predictors in this group (Coulter and McPherson, 1986). Moreover, the experience of adverse medication side-effects may be important determinants of adherence to medication in this group (Budd et al. 1996; Hogan et al. 1983). *Concerns* about immediate side-effects may therefore be much more important than the future-oriented concerns about dependence or long-term adverse effects measured by the *Specific-Concerns* construct.

This highlights two deficits within the current study. The first relates to the failure to incorporate variables from existing models such as the HBM and TRA as recommended in the literature (Marteau and Johnston, 1987). The justification for this omission was that the aim study was to explore the nature, determinants and effects of medication beliefs, rather than to identify the determinants of adherence. However, the salience of the medication beliefs described here depends on their association with adherence and the thesis is grounded within this domain and so the criticism of omission is justified. The second limitation relates to the *Specific-Concerns* construct. The items loading on this factor were derived from studies of patients with a variety of chronic illness and from informal interviews with renal and cardiac patients. It is perhaps not surprising that these were less salient for the psychiatric patients. Although as a group the psychiatric patients had higher *Specific-Concerns* scores than most other groups, other factors were clearly more influential in adherence decisions. These data suggest that although *Specific-Concerns* may be a core dimension of medication beliefs the content may vary. For example, the current experience of medication side-effects may be of greater concern for psychiatric patients than for patients with asthma. Asthma patients on the other hand may be more worried

about the long term harmful effects of their steroid inhaler than about the current experience of side-effects which are minimal.

10.2.3 The specificity of associations between beliefs and reported adherence

A further analysis, conducted on the renal dialysis data set, suggested that the association between treatment beliefs and adherence behaviour was highly specific. The key finding to emerge was that specific beliefs were related to specific reported adherence behaviours in a meaningful and discriminating way. For example, concerns about prescribed medication were associated with lower rates of self-reported medication adherence but not with lower adherence to fluid and dietary restrictions. Similarly, patients who believed that their fluid and dietary restrictions were too strict were less likely to adhere to them. Furthermore, the observation that adherence to medication was not correlated with adherence to fluid/diet restrictions provided additional evidence that patients may adhere to some aspects of their treatment but not others. This reinforces the view that narrowing the focus of investigation to beliefs which are directly related to the behaviour in question might enhance that explanatory power of psychological models (Marteau, 1995).

10.2.4 The relative effect of illness and medication beliefs on active and passive nonadherence

The literature identified two broad categories of adherence behaviour. For some patients nonadherence was a strategic attempt to control aspects of the illness or treatment by deliberately altering the amount of medication used (Morgan and Watkins, 1988; Conrad, 1985). This was labelled *Active* nonadherence to distinguish it from a more *Passive* type of nonadherence attributed to a lack of motivation to remember to take the treatment or to the presence of barriers which prevent the patient from carry out their intention to take the medication as instructed.

In Study 3, Chapter 8, the key predictors of reports of passive and active non adherence to medication were identified from the results of two multiple linear regression analyses, using reported AnA and PnA as the respective dependent variables in the asthma clinic sample. Medication beliefs had a stronger effect on adherence than beliefs about asthma (as defined by Leventhal's five components of illness representation) or perceptions about future control over the disease. AnA was predicted by perceived lack of empathy from medical and nursing staff, concerns about the prescribed medication as a whole and

younger age. PnA was predicted by younger age and weaker beliefs in the necessity of asthma medication for maintaining health. These findings will now be discussed in more detail

Passive nonadherence and the perceived salience of medication

Although only medication beliefs were retained in the regression analysis, both medication and illness representations were associated with passive nonadherence as indicated by the reported frequency of forgetting to take medication. The pattern of correlation between illness and medication beliefs and PnA suggested that these beliefs contributed to the patient's perceptions of the *salience* of their medication which was in turn related to how often they forgot to take it. Patients who believed that their asthma would last along time and have severe personal consequences also had stronger beliefs in the necessity of their prescribed medication and reported lower rates of PnA.

Active nonadherence as self-regulation

In his qualitative study of medication beliefs in epilepsy Conrad (1985) noted that patients adjusted the amount of medication they took in attempt to gain control over the illness or to avoid becoming "too dependent on their anticonvulsant medication. In the present study, the differential effect of beliefs about medicines, beliefs about illness and locus of control over asthma on reports of Active (AnA) and Passive (PnA) suggest that this form of "self-regulation" is more widespread.

The observation that *Specific-Concerns* were predictive of the reported frequency of deliberately altering the dose of medication but not of forgetting it is consistent with self-regulatory theory. It supports Leventhal's view of the patient as an active problem solver whose behaviour represents an attempt to minimise perceived threat by employing specific coping procedures (Leventhal et al. 1992a), in this case taking less medication in an attempt to lessen the risk of dependence and long term effects. The fact that medication representations had a more direct effect on adherence than illness beliefs has implications for the further development of the SRM and this will be discussed later in this chapter.

A further point of note in these data was the effects of perceived lack of empathy from medical and nursing staff (PLE) on AnA to medication. This implies that adherence decisions arose from a rather complex interplay between personal beliefs about treatment and views about the quality of the patient-practitioner relationship. This finding suggests

that adherence may best be understood by an approach which combines SCMs, SRM and features of the communication model exemplified by the work of Ley (1988, 1982).

Before accepting this premise it is important to rule out possible confounders. The logically consistent interactions between the PLE construct, Specific concerns and reported adherence might simply reflect a response bias. Budd (1987) has identified this as a potential problem in questionnaires assessing the TRA. He suggests that the TRA forms part of a 'intuitive lay psychology of intention' and that people filling out questionnaires assessing TRA components will attempt to create consistency between their responses, so appearing to validate the model. A similar process could account for the apparent coherence between beliefs and reported behaviour observed in the present study. However, the differential effect of beliefs on AnA and PnA mitigates against this explanation. An opposing view is that the TRA is part of our 'intuitive model of intention ' because it reflects real psychological processes and fundamental interactions between the way in which people think and behave and the same could be true of the interactions noted in the present study. Moreover, an attempt was made to diminish the influence of ordering effects by not presenting items in "conceptual" order within the questionnaire. However, the possibility that ordering effects were present within these data cannot be totally discounted given that this was a cross-sectional study. Further studies are needed to clarify this issue. A prospective design in which assessment of cognition and adherence were temporally separated would reduce patterned responses. However, prospective studies may pose different problems as discussed under Implications for further research.

10.3 The determinants of medication beliefs

Marteau and Johnston (1986a) have suggested that interventions to change dysfunctional beliefs could address factors which influence their formation. The studies described above provide preliminary evidence that beliefs about prescribed medication , especially concerns about the potential for dependence, long-term effects and disruption are associated with nonadherence. Correlation coefficients between the BMQ factors computed during psychometric testing showed that *Specific-Concerns* are related to negatives beliefs about medicines as whole. However, it is clear from the small size of the correlation coefficients obtained that these are not the only determinants of concerns. The final section of the empirical work was therefore devoted to an exploration of some of the possible determinants of medication beliefs, with particular emphasis on Specific medication beliefs as these were more strongly related to adherence than beliefs about medicines as a whole.

10.3.1 The perceived effect of medication on illness symptoms as a determinant of Specific-Necessity beliefs

The selection of variables for initial evaluation as potential determinants was informed by theory. Pennebaker (1982), has shown that illness-related cognitions and the interpretation of physical symptoms are closely related . Self-regulatory theory posits that illness representations and the selection and appraisal of coping procedures are influenced by current and past experience of symptoms (Gonder-Frederick and Cox, 1991; Love et al. 1989; Leventhal et al. 1986). Thus, one question was whether representations of medicines might also be influenced by their perceived effects on symptoms. In particular, it was anticipated that a perception that prescribed medication made one "feel better" by improving symptoms would result in stronger beliefs in its necessity. The determinants of each BMQ factor which were identified in this study imply that patients' ideas about medication are coherent in "common-sense" terms. For example, patients were more likely to have strong beliefs in the necessity of their medication if it was perceived to affect their symptoms. Similarly, necessity beliefs tended to be stronger with more medicines prescribed. There is evidence that some patients use the number of medicines prescribed for them as an indication of disease severity (Donovan and Blake, 1992; Morgan and Watkins, 1988, Leventhal et al. 1991). Presumably, this in turn, influences the perception of the necessity of their medication.

10.3.2 Perceived susceptibility to the adverse effects of medication and reported experience of medication side-effects as determinants of Specific-Concerns

Earlier studies had identified patient concerns about the potential adverse effects of prescribed medication. This implies a perception of medication side effects as a health threat. The Health Belief Model suggests that notions of perceived *susceptibility* may influence these concerns. A Sensitive Soma scale (SS) was therefore used to assess perceived susceptibly to the adverse effect of medication on symptoms. In the present study, cognitive variables such as the perceived effects of medication on symptoms and perceived susceptibility to the adverse effects of medicines were far stronger determinants of the core dimensions of medication representation than were the socio-demographic variables studied. Although age and educational experience were determinants of *Specific-Concerns* and age of *General-Harm* they added little to the explained variance in these dimensions

The key determinants of *Specific-Concerns* were beliefs about the harmful nature of medicines in general (*General-Harm)* and beliefs about personal susceptibility to such effects (Sensitive Soma). The *General-Harm* factor may represent a prototypic view of medication, analogous to the disease prototypes noted in studies of lay representation of illness (Bishop, 1987; Bishop and Converse, 1986).

Further studies investigating relations between reported past and present experience of medication side-effects suggested that *Specific-Concerns* had both abstract (perceived susceptibility and concrete (past or present experience of medication side-effects) antecedents. This finding is consistent with self-regulatory theory which proposes that illness representation have abstract (e.g. an illness label- asthma) and concrete (e.g. shortness of breath) components. The SRM suggests that the experience of symptoms plays a pivotal role in the formation of illness representations (Cameron et al. 1993; Baumann et al. 1989). The finding in the present study, that the perceived effect of medication on symptoms accounted for a significant proportion of the variance in *Specific-Necessity* beliefs, provides tentative support for the notion that medication belief are also partially determined by symptom experience.

However, limitations in the design of this simple exploratory study mean that the finding must be interpreted with caution. The relationship between disease schema and symptom experience may be bi-directional. For example, being given information that one has a disease may initiate a search for confirmatory symptoms (Bishop et al. 1987; Pennebaker, 1982). It is difficult to identify causal relationships between medication beliefs and symptomatic experience. Underlying concerns about medication might stimulate a search for confirmatory "side-effects". Similarly positive perceptions that medication makes one feel better might be stimulated by strong beliefs in its necessity (Lundh, 1987).

10.3.3 Cultural factors and medication beliefs?

The final section of the empirical work (Section 9.6), investigated the effects of cultural factors on beliefs about medicines in general in 600 undergraduate students. Course of study- as a marker of 'professional cultural group' and stated cultural origin were predictors of beliefs about medicines in general but not of beliefs about personal *susceptibility* to their adverse effects. Asian students were significantly more likely to perceive medicines as intrinsically harmful and it is possible that participants who assigned themselves to be of Asian cultural origin may have been influenced in their views about

medicines by the Hindu Ayuvedic system of medicine which stresses notions of balance and "herbal" rather than pharmaceutical treatments (Hawthorne et al. 1993; Keltner and Folks, 1992, Khajuria and Thomas, 1992; Uba, 1992).

A rather striking finding was that pharmacy students have significantly more positive views about medication than all other groups, even when controlling for cultural origin. This is consistent with previous observations that the beliefs of health practitioners (or in this case-student practitioners) may be differ from their patients (Johnston and Marteau, 1987) and reinforces the need to focus greater attention on the beliefs of health practitioners as determinants of care and of patient cognition and behaviour (Marteau and Johnston, 1986b; Marteau and Johnston, 1987). Before summarising the theoretical implications of the empirical section of the thesis I will outline some of the major limitations and implications for further studies.

10.4 Limitations of the empirical work

The empirical work contributing to this thesis has several limitations many of which have been described in the relevant empirical sections of the thesis. However, it is worth drawing attention to significant methodological limitations which need to borne in mind when considering the implications of the findings.

10.4.1 Measurement of medication adherence

In common with most "measures" of adherence, self-report does not detail the exact number of medications taken. Moreover, the accuracy of self-report has been questioned on the grounds that patients may be reluctant to admit to non-adherence and that it generally tends to over-estimate adherence by about 20% (Caron, 1985). However, others have suggested that self-report is a useful method for grading patients according to their "relative standing on the adherence dimension" (Haynes et al, 1980; Ley, 1995). Adherence questions were phrased in a non-threatening way so as to diminish self-presentational bias and located in two different places within the questionnaire to limit ordering effects. A further attempt to improve the validity of patients' self-report was the use of continuous scales rather than simple dichotomous variables and checking that the internal reliability and test-retest reliability of the scales was adequate.

The test-retest reliability of the RAM scale was within acceptable limits, but it has not been fully validated against other measures of adherence behaviour and it may be that high scores on the RAM scale are representative of negative attitudes to the treatment programme as a whole rather than a true estimate of adherence to medication. This hypothesis was tested in Study 8.2 in which the effects of treatment beliefs on adherence was assessed for two separate components of a haemodialysis treatment programme. Despite these measures it should be recognised that the RAM has not been fully validated by comparison with other adherence measures. Until this is achieved, the results of this study should be interpreted with caution and any conclusions reached about the effects of medication beliefs on adherence are preliminary.

10.4.2 Cross-sectional design

The cross-sectional design of this study represents a further limitation in that one cannot be sure about the direction of influence between beliefs and reported behaviour. Thus, the predictive effect of medication beliefs on medication behaviour should now be examined using a longitudinal study design. However, the optimum separation of assessments of beliefs and behaviour over time is by no means clear especially in relation to "feedback" models such as the SRM. It may be that today's beliefs have a greater impact on today's behaviour than yesterday's beliefs. However, this point does not obviate the fact that the inclusion of a prospective study would have strengthened the empirical section of this thesis. Most of the work focused on beliefs and adherence in chronic illness and it is likely that inter-relations between beliefs and behaviour would have stabilised in such patients and would not fluctuate greatly. Therefore, separating belief and adherence measures, even by a week or so, would have proved advantageous, even if only to reduce the possibility of response bias.

10.4.3 Lack of cross-checks for confounding variables

The 'logically coherent' relationships observed within the various data sets may be partially attributed to the respondent's ability to understand that certain constructs logically belong together and a subsequent desire to appear consistent in their responses (Sheeran and Orbell, 1996). In an attempt to diminish the influence of ordering effects, items were not presented in 'conceptual' order in that items expressing a particular view were not grouped together. In order to diminish any effects of perceived social desirability of certain responses, questionnaire items were presented in a context which sanctioned the respondents 'personal views' and assured the anonymity and confidentiality of responses

(Abraham and Hampson, 1996). However, there is no way of checking whether this had been successfully achieved. Furthermore it is known that desire for social acceptance varies between individuals. Thus there is a possibility that social desirability bias may have influenced response, particularly to the RAM and *Specific-Necessity* scales. The methodology would have been strengthened by the inclusions of cross-checks, such as the Marlowe Crowne measure of social desirability, (Reynolds, 1982) and subsequent cross-comparison between social desirability scores and other variables, particularly self-reported adherence and *Specific-Necessity* scores

The association of negative views about illness and medication raises the question of whether these are manifestations of common underlying state characteristics such as depression or hopelessness or personality traits such as pessimism and cynicism. Recent studies investigating the role of personality in symptom reporting have shown that the trait characteristic of Negative Affectivity (NA) is associated with increased symptom reporting (Watson and Pennebaker, 1991). Trait NA individuals tend to focus on the negative side of things , having a less favourable self image and a greater tendency to depressed mood and reduced satisfaction with life. Thus it follows that trait NA individuals might tend towards a more negative view about their illness and treatment as well as of medication in general. Including a measure of trait NA would have allowed a check on whether the observed relationships between negative attitudes to general and specific medication and to low adherence were explained by high Trait NA.

10.5 Implications for future research

The empirical studies described in Chapters 7 to 9 provide an insight into the nature, effects and determinants of specific and general medication beliefs. However, this is a relatively new area of investigation and the results described are limited and preliminary. A priority for future research therefore is to confirm some of the above findings on other data sets while addressing the key methodological limitations within the current design. In particular, prospective studies are needed to examine how specific medication beliefs develop during the course of a chronic illness and how they relate to more general beliefs about medicines as a whole. Additionally, there is need for prospective longitudinal studies to clarify the dynamic interaction between patients' representations of illness and treatment and their adherence to treatment over time. One hypothesis is that beliefs about general and specific medication will influence treatment preferences and initial orientation to prescribed medication. However, continued adherence will be determined

by a dynamic interplay between abstract beliefs and concerns about medication and the degree to which the patient's concrete experience of symptoms is influenced by the medication.

There is need to evaluate interactions between medication beliefs adherence and other social cognition variables, particularly normative beliefs. Such studies could also be used to investigate the possible mechanisms of the observed association between younger age and lower reported adherence. Thus future researchers may wish to incorporate the BMQ factors as belief variables within the TRA/TPB and HBM detailed earlier in this chapter

An important question which were not thoroughly addressed in this preliminary study is whether patients form beliefs which are specific to individual medicines (e.g. aspirin) or types of medication (e.g. analgesics) and how such beliefs might relate to the core dimension of Necessity and Concerns. For example, patients may have concerns about particular medicines which are distinct from the beliefs about dependence, long-term effects and disruption which comprise the *Specific-Concerns* dimension. One example may be the notion that analgesics loose their efficacy if taken regularly for long periods of time (Lorish et al 1990). It may be that differential beliefs about individual aspects of the treatment might explain the variance in adherence to individual component treatment regimens. This work is also needed to determine whether the failure of the *Specific-Concerns* to predict adherence in the psychiatric clinic sample can be attributed to the items currently included in this factor or whether the construct itself is flawed. A theoretical suggestion is that the *Specific-Concerns* construct is valid for a range of treatments (e.g. antibiotic medications, surgery and physiotherapy) and situations but the actual concerns loading on this dimension will differ between individuals and across treatments. A similar argument may apply to the *Specific-Necessity* construct. Thus a focus for future investigations is to establish the type of concerns which are most salient in particular situations.

This draws attention to a more fundamental questions relating to the cognitive representations of medication. For example, how do people arrive at the view that their prescribed medication is "necessary" or a cause of concern? The components underlying the cognitive representations of illness (e.g. timeline, causes, consequences,) might also underpin representations about necessity of medication or concerns about potential dangers (Leventhal, in press) and this is an empirical question. A further line of inquiry for future research is a more detailed investigation of individual concepts loading on the four

dimensions described above. This might include a more detailed exploration of the cognitive process underlying individual concepts, within the core constructs identified by PCA. For instance, what to patients mean by "dependence" and "addiction"? These terms appear to be used interchangeably by patients in the studies reported to date, yet we know little about whether these concepts are differentiated or how people judge the "dependence potential" of medication?

Although this thesis has focused on medication beliefs, the findings emphasise the importance of patients' beliefs about treatment in general, and justify further investigation of patients views about individual treatment options. In particular, we need to establish the extent to which representations of individual treatment options are accurate and are predictive of future adjustment and adherence. Here it may be particularly salient to explore patients' perceptions of relative risk associated with various treatment modalities and this may have implications for the issue of informed consent and shared decision making. The BMQ constructs may also form the basis for an investigation of the role of treatment representations in the placebo effect. The clinical importance of placebo effects is well recognised (Horwitz et al. 1990; Horwitz and Horwitz, 1993), but the phenomenon is poorly understood and further studies are needed to gain a fuller understanding of the psychological mechanisms underpinning this effect.

Future studies might address the determinants of beliefs about medicines in general. The study of the medication beliefs of undergraduate students described above, suggested that students had fairly firm ideas about medication before attending university. Further studies are needed to verify this and establish the origins of medication beliefs among children and adolescents.

Finally, finding associations between medication beliefs and reported adherence raises the question of how amenable these beliefs are to change and whether changing beliefs alter adherence. Such questions are of fundamental importance to the future development of this area of research.

10.6 Theoretical implications

The limitations of the empirical work described within this thesis mean that any conclusions drawn from the data are tentative. However, the preliminary findings relating to the nature, effects and determinants of medication beliefs in chronic illness have several theoretical implications. These are linked to SCMs and self-regulatory theory.

10.6.1 Social Cognition Models (SCMS)

Health Belief Model (HBM) In most of the illness samples studied *necessity* beliefs and *concerns* seem to function in an analogous way to the *benefit* and *barriers* dimensions of the HBM which were found to influence medication adherence in previous studies (Ried et al. 1985; Ried and Christensen, 1988; Harris and Linn, 1985). The HBM has been criticised for not specifying the cognitions which underpin the cost-benefit analysis implicit in the benefit/barriers constructs (Leventhal, 1993). The observation that the BMQ-Specific scales were associated with reported adherence to medication suggests that in applying the HBM to medication adherence the benefit construct might be operationalised as *Specific-Necessity* beliefs and the barriers as *Specific-Concerns.*

Theory of Reasoned Action/Theory of Planned Behaviour (TRA/TBP) The fact that relevant cognitions about medication (e.g. efficacy, tolerance), are not included in the BMQ factors confirms that they do not represent the only components of cognition about medicines. However, it is suggested that the General and Specific factors represent the core dimensions of beliefs which inform peoples' attitudes about medication. As such the BMQ factors may be incorporated into the TRA/TPB as belief constructs. Notions of *necessity* and *concerns* about negative effects underpin attitudes to prescribed medication. Peoples' attitudes towards medicines in general are informed by views about the intrinsic nature of medicines and the way in which they are used within society.

As mentioned earlier in this chapter, the use of the term "worry" in the *Specific-Concerns* items, adds an affective element to the cognitive dimension. Eagly and Chaiken (1993) conceptualise attitudes as tri-dimension having a cognitive, affective and conative component It is possible that beliefs about *Specific Necessity* (e.g. "My medicines are

necessary for health") and *Specific-Concerns* ("I sometimes worry about the long-term effects of my medicines") are the key determinants of the patient's attitude (e.g. positive or negative orientation to prescribed medication). Furthermore the findings of this study suggest that the conative dimension might be manifested as the degree of willingness to take medication according to the prescriber's instructions (indicated by reported adherence)

Control beliefs In the asthma clinic sample, reported adherence to medication was more strongly associated with necessity beliefs and concerns than with beliefs about control over asthma. However, when control beliefs were made very specific to the behaviour (ie "*Whether my asthma gets better or worse depends on well my medicines work*") these were then correlated with reported adherence. The findings suggest patients own beliefs about their illness and treatment may have a more direct influence on medication adherence in chronic illness that notions of internal vs external control.

10.6.2 Self-regulatory model (SRM)

The key finding in relation to the SRM was that in the asthma data set, representations of prescribed medication were more strongly associated with reported adherence than illness representations. However, the relationships between medication beliefs and reported adherence were broadly consistent with self-regulatory theory, particularly the finding that *Specific-Concerns* were associated with strategic alterations in the medication dose (active nonadherence). This seems to be an attempt to reduce the perceived risk by taking less and implies that active nonadherence is a coping procedure in response to the potential adverse effects of medication as a perceived threat to health. This is consistent with Leventhal's notion of the patient as an "active problem solver" and with the selecting of coping strategies based on representations of health threats.

A further point of theoretical interest is that illness and medication representations were related in a logically consistent pattern (e.g. those who believed their illness would be long-lasting with severe consequences had stronger beliefs in the necessity of their medication). However beliefs about prescribed medication were stronger predictors of reported adherence than illness beliefs suggested that the utility of the SRM as a framework for understanding treatment adherence may be enhanced by inclusion of treatment beliefs. The preliminary data described in thesis suggest that medication beliefs may have concrete and abstract dimensions and be influenced by past and present experience in a similar way

to illness representations (Leventhal et al 1992a). Moreover, beliefs about prescribed medication correlated, albeit fairly weakly, with coping procedures (adherence) and indicators of subjective appraisal. The use of the term "worry" to elicit *Specific-Concerns* hints that representations of medication may also have emotional as well as cognitive dimensions. Figure 10.1 shows the theoretical inter-relations between existing components of the SRM and treatment representations based on the preliminary findings described above.

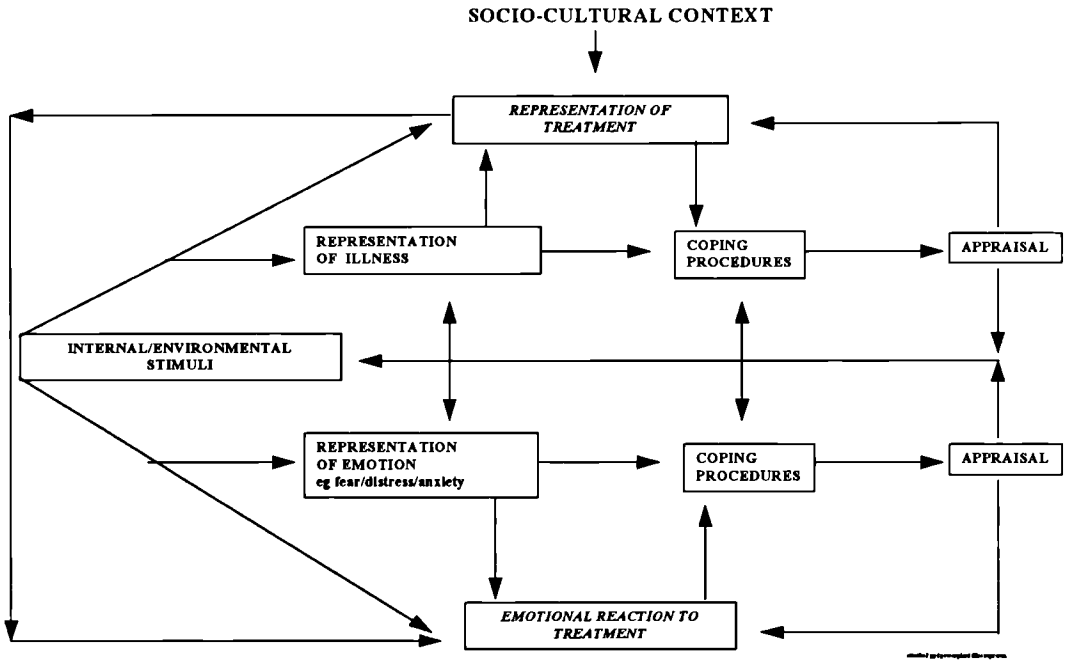


Figure 10.1: Illustration of how treatment beliefs may be incorporated into Leventhal's SRM

A further point of relevance to self-regulatory theory relates to the notion of disease prototypes. The fact that people seemed to have broad, and fairly complex ideas about medicines as whole (represented in the *General-Harm* and *General-Overuse* constructs) is somewhat similar to the disease prototypes described by Bishop and colleagues (Bishop and Converse, 1986; Bishop et al. 1987). These are models of particular diseases derived from personal exposure to past episodes or from more general assumptions about the typical characteristics of a disease. Prototypic beliefs about disease inform the interpretation of symptoms or information. For example, a person who accepts that "coughs and sneezes spread diseases" might believe that all infectious diseases are transmitted in this way. Their prototypic view of infectious diseases as airborne might

make them reluctant to work closely with someone who is HIV positive. It may be the BMQ-General factors represent prototypic views about the intrinsic nature of medicines and how they are used.

The empirical finding that these beliefs were related to indicators of "cultural grouping" supports Landrine and Klonoff (1992) suggestion that the impact of culture on health-related beliefs deserves more attention.

10.7 Implications for practice

Significant correlations were observed between medication beliefs and reported adherence across a range of chronic illness groups. Although, the limitations of the methodology used suggest the need for a cautionary approach when generalising from these findings, the preliminary research described in thesis has identified the types of medication beliefs which are associated with nonadherence. These beliefs may now form the target of interventions to enhance adherence. What would be the nature of these interventions?

There is currently increasing interest in the inclusion of detailed standardised information leaflets as part of the packaging of medicines. This thesis might inform this initiative in two ways. First, by providing measures to assess the impact of this type of information on patients' representations of medicines especially *Specific-Concerns*. This is necessary because, although the aim of improving patient access to medicines information is laudable, standardised information alone may not meet the needs of all patients (Weinman, 1990). Moreover, *Specific-Concerns* may arise from individual beliefs about the potential for dependence or long-term effects which might not be dealt with in the leaflet and it may therefore be appropriate to include this type of information in package inserts. Secondly, patient education about medicines is likely to be enhanced if health professionals, such as doctors and pharmacists, elicit patients' own concerns about their medication and address these issues on an individual basis rather than by relying on standardised written information alone.

Although a recent study has described an intervention which enhanced adherence to antipsychotic medication by targeting cognitions (Kemp et al, 1995) , this was time-consuming requiring, over 5 hours per patient. Although this may seem like an excessive outlay of resources, the input of resources to enhance adherence should be balanced against the costs of nonadherence. Over the course of a chronic illness such an outlay may

be justified. However, intensive "therapy" to change negative attitudes to prescribed medication may not be necessary. An alternative approach may be to elicit patients' views early on. This might uncover initial preferences and concerns and open a dialogue between patient and practitioner in which subsequent problems may be addressed. Allowing patients to feedback the effects of treatment during regular periodic review of the medication may limit the formation of mistaken beliefs and exaggerated concerns and so facilitate adherence.

Barber (1991,1995) has suggested that respecting patient choices is essential to good prescribing. In practice, this should entail closer attention to the patients initial perspective on medication with periodic feedback of experiences and concerns. Eliciting patients' beliefs about their medicines may provide the basis for closer partnership in medicine taking (Royal Pharmaceutical Society of Great Britain, in press).

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Appendix I
Letter of introduction to study participants

ASTHMA RESEARCH STUDY
Brighton Health Care & University of Brighton
Hove General Hospital
Sackville Road
HOVE

Dear Patient,

I am writing to tell you about a research study which we are undertaking with our colleagues from Brighton University. We are trying to find out more about patients' views of asthma and its treatment and the effects of this upon their lives. We would like to invite you to take part in this study.

The study will involve a brief interview with a researcher when you attend your out-patient appointment at Hove General Hospital. The researcher will ask you to fill out a questionnaire regarding your views about asthma and its treatment. Filling out the questionnaire will mainly involve ticking boxes and will take about twenty minutes. Two weeks after your out-patient appointment, the researcher will send you a similar set of questionnaires to fill out at home. Again this will take about twenty minutes. You will be asked to return the completed questionnaires in a stamped address envelope provided by the researcher.

Any information you give will be **ANONYMOUS and CONFIDENTIAL** and will be seen only by the research staff. The questionnaires will not be seen by the doctors, nurses or other staff at the clinic.

There is no need for you to reply to this letter. You can simply tell the clinic receptionist whether you wish to be involved or not when you next attend the out-patient clinic at Hove. If you agree to take part in the study you can withdraw at any time without having to give a reason.

If you do not wish to take part or if you decide to withdraw after joining the study, this will not affect your care in any way.

Thank you for taking the time to consider this request,

Yours sincerely,

Robert Horne
ASTHMA RESEARCH STUDY

Appendix 2
Letter of introduction to psychiatric sample

South Downs Health
NHS Trust

New Sussex Hospital
Windlesham Road
Brighton BN2 3AS
Tel (0273) 725351

17th January, 1994

Dear patient

Two pharmacy colleagues and I are hoping to embark on a small study, looking at the advantages of giving patients more information about the medication they are receiving. In order to ensure that the questionnaires we plan to use are not bothersome , I wonder if you would be kind enough to spend 30-40 minutes seeing one of two colleagues, Mr Railton Scott or Mr Rob Horne, when you next come and see me. If you are willing and able to do this I would be grateful if you would let me know as soon as possible. I enclose a stamped, addressed envelope.

Your sincerely,

MICHAEL ROSENBERG
Consultant Psychiatrist

Appendix 3

The Illness Perception Questionnaire (IPQ) (Weinman et al, 1996)

Illness Identity (Core symptom list)

(Please indicate how frequently you now experience the following symptoms as part of your (illness) *Rated: All of the time, frequently, occasionally, never.*

Pain, Nausea, Breathlessness, Weight Loss, Fatigue, Stiff Joints, Sore Eyes , Headaches, , Upset Stomach, Sleep Difficulties, Dizziness, Loss of Strength

We are interested in your own personal views of how you now see your illness). Please indicate how much you agree or disagree with the following statements about your illness.
Rated: Strongly agree, agree, neither agree nor disagree, disagree, strongly disagree

Cause

- A germ or virus caused my illness
- Diet played a major role in causing my illness
- Pollution of the environment caused my illness
- My illness is heredity - it runs in my family
- It was just by chance that I became ill
- Stress was a major factor in causing my illness
- My illness is largely due to my own behaviour
- Other people played a large role in causing my illness
- My illness was caused by poor medical care in the past *
- My state of mind played a major part in causing my illness*

*(N.B. The last two cause items have been added since some of the earlier studies and hence do not appear in table 6).

Time-line

- My *illness* will last a short time ®
- My *illness* is likely to be permanent rather than temporary
- My *illness* will last for a long time

Consequences

- My *illness* is a serious condition
- My illness has had major consequences on my life
- My *illness* has become easier to live with ®
- My *illness* has not had much effect on my life ®
- My *illness* has strongly affected the way others see me
- My *illness* has serious economic and financial consequences
- My *illness* has strongly affected the way I see myself as a person

Control/Cure

- My *illness* will improve in time.
- There is a lot which I can do to control my symptoms
- There is very little that can be done to improve my *illness* ®
- My treatment will be effective in curing my *illness*
- Recovery from my *illness* is largely dependent on chance or fate ®
- What I do can determine whether my *illness* gets better or worse

® = Reversed Scoring

Appendix 4

Perceived Control Over Asthma Scale

(Adapted from Perceived Control Over Recovery Scale (Partridge& Johnston, 1989)

R1 How I manage in the future depends on me not on what other people can do for me.

R2 It is often best to just wait and see what happens.

R3 It's what I do to help myself that's really going to make all the difference.

R4 My own efforts are not very important, control over asthma really depends on others.

R5 It is up to me to make sure I control my asthma as well as possible under the circumstances.

R6 My own contribution to the control of my asthma doesn't amount to much.

R7 Controlling my asthma now is a matter of my own determination rather than anything else.

R8 I have little control over my progress from now on.

R9 It doesn't really matter how much help you get, in the end it's your own efforts that count.

Cronbach alpha =0.68 (0.73 if R2 removed)
R2, R4, R6 and R8 are reverse scored
High scores indicate high internal control beliefs
Low scores indicate high external control beliefs

Appendix 5

Sample of study questionnaire showing orginal pool of 34 medication belief items and 4 RAM scale items

What the questionnaire is about

- This questionnaire will help us to find out more about what you think about medicines.
- There are no right or wrong answers to the questions.
- We are interested in your personal views rather than what your doctor or anyone else might think.

This questionnaire is completely confidential.
It will be seen only by the researchers and not by any of the staff who are looking after you.

How to fill it out

- Please answer the questions as completely and honestly as possible.
- Most of the questions can be answered by ticking a box
- Answer each of the questions in turn
- Please don't feel that you have to spend a long time over each question. Often the first answer that comes to you is the best.
- Please answer every question
-

WHAT WE MEAN BY MEDICINES

In this questionnaire we talk about "medicines". By medicines we mean all tablets, pills, inhalers, liquids, creams, injections etc that have been prescribed for you.

YOUR VIEWS ABOUT MEDICINES FOR ASTHMA

We would like to ask you about your **personal views** about **medicines for asthma.**
These are statements other people have made about **medicines for asthma.**
Please show how much you agree or disagree with them by ticking the appropriate box.

There are no right and wrong answers.
We are interested in your personal views

	VIEWS ABOUT MEDICINES FOR ASTHMA	STRONGLY AGREE	AGREE	UNCERTAIN	DISAGREE	STRONGLY DISAGREE
MA	My health, at present, depends on my medicines					
MA2	Having to take my medicines worries me					
MA3	My life would be impossible without my medicines					
MA4	My medicines are powerful					
MA5	Without my medicines I would be very ill					
MA6	I sometimes worry about the long-term effects of my medicines					
MA7	My medicines are a mystery to me					
MA8	My medicines are effective					
MA9	I would like to change my present treatment					
MA10	I am in control of my medication					
MA	Whether I feel better or worse depends on my medicines					
MA 2	I sometimes forget to take my medicines					
MA13	My medicines disrupt my life					
MA 4	My medicines make me feel better					
MA 5	I sometimes alter the dose of my medication to suit my own needs					
MA16	I sometimes worry about becoming too dependent on my medicines					
MA17	My health in the future will depend on my medicines					
MA 8	I can cope without my medicines.					
MA 9	My medicines protect me from becoming worse.					
MA20	It is difficult for me to take my medicines in exactly the way my doctor told me					
MA2	I cannot always trust my medicines					
MA22	I have been given enough information about my medicines					

Note: the print size of this questionnaire has been reduced to fit this page

QUESTIONS ABOUT TAKING MEDICINES

Most people find a way of using their medicines which suites them. We would like to ask you a few questions about how you use your medicines

1) Some people forget to take their medicines. How often does this happen to you ?

Very often ..... Often ..... Sometimes ..... Rarely ..... Never .....

2) Some of the people I have talked to say that they miss out a dose of their medication, or adjust it to suit their own needs. How often do you do this ?

Very often ..... Often ..... Sometimes ..... Rarely ..... Never .....

3) If you DON'T do this can you explain why not?

.....

.....

.....

.....

.....

.....

YOUR VIEWS ABOUT MEDICINES IN GENERAL

These are statements that other people have made about medicines in general.
Please show how much you agree or disagree with them by ticking the appropriate box.

There are no right and wrong answers.
We are interested in your personal views

	VIEWS ABOUT MEDICINES IN GENERAL	STRONGLY AGREE	AGREE	UNCERTAIN	DISAGREE	STRONGLY DISAGREE
G1	Without medicines doctors would be less able to cure people					
G2	Newer medicines are more effective than older ones					
G3	Most medicines are addictive					
G4	People who take medication should stop their treatment for a while every now and again					
G5	Medicines only work if they are taken regularly					
G6	Medicines do more harm than good					
G7	Medicines are not natural remedies					
G8	All medicines are poisons					
G9	It is better to do without medicines					
G10	Natural remedies are safer than medicines					
G11	Stronger medicines are more dangerous than weaker medicines					
G12	Medicines are a necessary evil					
G13	Doctors place too much trust on medicines					
G14	If doctors had more time with patients they would prescribe less medicines					
G15	There is a big difference between a medicine and a drug					
G16	The medicine you get is more important than the doctor you see					
G17	Doctors use too many medicines					
G18	Most medicines are safe					

Appendix 6

Self-Rated Health Scale

(Jenkinson et al. 1994; Ware, Jr. and Sherbourne, 1992).

In general, would you say your health is:

1 poor
2 fair
3 good
4 very good
5 excellent

Compared to one year ago, how would you rate your health in general now:

1 much worse now than one year ago
2 somewhat worse now than one year ago
3 about the same as one year ago
4 somewhat better now than one year ago
5 much better than one year ago

- During the past 4 weeks, how much of the time has your physical health interfered with your normal social activities with family, friends, neighbours or groups?

1 all of the time
2 most of the time
3 some of the time
4 a little of the time
5 none of the time

The following four items are included and scored from 1 to 5 where 1 = Definitely true, 2 = Mostly true, 3 = don't know, 4 = Mostly false and 5 = Definitely false

- I seem to get ill a little more easily than other people
- I am as healthy as anybody I know®
- I expect my health to get worse
- My health is excellent®
-

® Items are reverse scored

Appendix 7

Pearson and Spearman correlations for BMQ factors and adherence for cardiac (n=115) and dialysis (n=47) groups

BMQ scales	Cardiac Sample (n=115)		Renal Sample (n=47)	
	r	rho	r	rho
Specific-Necessity	-0.21	-0.20	-0.04	-0.02
Specific-Concerns	0.26	0.20	0.40	0.39
General-Harm	0.17	0.16	0.32	0.25
General--Overuse	0.19	0.17	0.30	0.30

Appendix 8

Principal Components Analysis (PCA) of items assessing beliefs about prescribed medication(Specific)

Beliefs about prescribed medication (Specific):

Exploratory factor analysis

Sample

120 hospitalised patients with a diagnosis of chronic heart disease

Demographic details

Sex	
Male (n)	85
Female (n)	35
Age (years)	
Mean	63.6
SD	12.4
Educational experience (%)	
Secondary	81.4
Tertiary	11.5
Higher	7.1
Number of regular medicines	
mean	3.5
range	1 - 14
mode	3.0
Number of hospital stays over last year	
mean	1.7
range	0 - 8
mode	1.0
Number of GP visits over last year	
mean	6.5
range	0 - 24
mode	6

Item pool of 18 statements about prescribed medication (specific subjected to PCA showing mean and standard deviation for the Cardiac sample (n=120)

Statements about prescribed medication	Mean	SD
It is difficult for me to take my medicines in exactly the way my doctor told me	2.09	.75
My medicines disrupt my life	2.31	.92
Having to take medicines worries me	2.70	1.07
I sometimes worry about becoming too dependent on my medicines	2.82	1.10
My medicines are a mystery to me	3.00	.98
I sometimes worry about the long-term effects of my medicines	3.11	1.15
My medicines are powerful	3.33	.77
I would like to change my present treatment	3.44	1.01
My life would be impossible without medicines	3.51	.95
My health in the future will depend on medicines	3.62	.93
I can cope without my medicines	3.62	.96
Without medicines I would be very ill	3.66	.88
I am in control of my medication	3.73	.85
My medicines protect me from becoming worse.	3.91	.71
My medicines are effective	3.94	.56
My health, at present, depends on medicines	4.03	.73

Exploratory factor analysis: Stage 1

Method
Principal components analysis
Non-orthogonal rotation (Oblimin)
Eigenvalues < 1 rejected.

16 items entered gave four-factor solution, accounting for 53.0 % of variance.
Four items rejected because Kaiser Meyer Olkin (KMO) statistic <0.7

Questionnaire item	KMO statistic
My medicines are powerful	0.58
It is difficult for me to take my medicines in exactly the way my doctor told me	0.66
I would like to change my present treatment	0.51
I am in control of my medication	0.69

Exploratory factor analysis: Stage 2

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.38	28.2	28.2
2	2.30	19.1	47.3
3	1.07	8.9	56.2

Structure matrix

Questionnaire item	Factor 1	Factor 2	Factor 3
Without medicines I would be very ill	**0.80**	0.09	0.21
My life would be impossible without medicines	**0.79**	-0.16	0.30
My health in the future will depend on medicines	**0.68**	-0.16	0.19
I sometimes worry about the long-term effects of my medicines	0.04	**0.82**	-0.06
Having to take medicines worries me	-0.07	**0.81**	-0.30
I sometimes worry about becoming too dependent on my medicines	-0.11	**0.71**	-0.19
My medicines disrupt my life	0.19	**0.61**	-0.41
My medicines are effective	0.29	-0.14	**0.73**
My medicines are a mystery to me	0.28	0.41	**-0.62**
My health at present depends on my medicines	0.41	-0.07	**0.57**
I can cope without my medicines	-0.22	0.48	**-0.50**
My medicines protect me from becoming worse	0.59	-0.13	**0.62**

Exploratory factor analysis: Stage 3

Method

Principal components analysis

Oblimin rotation

Forced two-factor solution

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.38	28.2	28.2
2	2.30	19.1	47.3

Structure matrix

Questionnaire item	Factor 1	Factor 2
My life would be impossible without medicines	**0.77**	-0.10
My medicines protect me from becoming worse	**0.75**	-0.21
Without medicines I would be very ill	**0.73**	0.14
My health in the future will depend on medicines	**0.64**	-0.09
My health at present depends on my medicines	**0.58**	-0.17
My medicines are effective	**0.55**	-0.29
Having to take medicines worries me	-0.22	**0.78**
I sometimes worry about the long-term effects of my medicines	-0.03	**0.73**
My medicines disrupt my life	-0.04	**0.68**
I sometimes worry about becoming too dependent on my medicines	-0.20	**0.65**
My medicines are a mystery to me	-0.06	**0.59**
I can cope without my medicines	-0.41	**0.54**

Exploratory factor analysis: Stage 4

Remove unsatisfactory items

I can cope without my medicines

High degree of spread

Factor 1	Factor 2
-.41	.54

My medicines are effective

High degree of spread

Factor 1	Factor 2
.55	-.29

Exploratory factor analysis: Stage 5

Method

Principal components analysis

Oblimin rotation

Reject Eigenvalues <1

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	2.85	28.4	28.4
2	2.27	22.7	51.1

Structure matrix

Questionnaire item	Factor 1	Factor 2
My life would be impossible without medicines	**0.81**	-0.09
Without medicines I would be very ill	**0.76**	0.14
My medicines protect me from becoming worse	**0.71**	-0.18
My health in the future will depend on medicines	**0.68**	-0.09
My health at present depends on my medicines	**0.58**	-0.15
Having to take medicines worries me	-0.20	**0.78**
I sometimes worry about the long-term effects of my medicines	-0.03	**0.77**
My medicines disrupt my life	-0.02	**0.69**
I sometimes worry about becoming too dependent on my medicines	-0.19	**0.68**
My medicines are a mystery to me	-0.01	**0.58**

KMO (sampling adequacy) = **0.75**

Bartlett's Test of Sphericity = **281.22** (P<**0.0001**)

BMQ-SPECIFIC: Replication of factor structure

1. Procedure

- Remove multivariate outliers Malanobis distance > 3 Std-dev from multi-dimensional mean
- Remove if > 5 items missing
- Re-factor on "cardiac" group
- Confirm factor structure on other diagnostic groups

BMQ-SPECIFIC: Replication of factor structure

2. Results

Cardiac group
(cleaned data n=114)

Method
Principal components analysis
Oblimin rotation
Reject Eigenvalues <1

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	2.85	28.5	28.5
2	2.40	24.0	52.5

Structure matrix

Questionnaire item	Factor 1	Factor 2
My life would be impossible without medicines	**0.81**	-0.06
Without medicines I would be very ill	**0.78**	0.09
My health at present depends on my medicines	**0.71**	-0.02
My medicines protect me from becoming worse	**0.67**	-0.19
My health in the future will depend on medicines	**0.62**	-0.11
I sometimes worry about the long-term effects of my medicines	0.00	**0.80**
Having to take medicines worries me	-0.18	**0.78**
I sometimes worry about becoming too dependent on my medicines	-0.19	**0.72**
My medicines disrupt my life	0.05	**0.67**
My medicines are a mystery to me	-0.01	**0.58**

BMQ-SPECIFIC: Replication of factor structure
Asthma sample
(cleaned data n=76)

Principal components analysis
Oblimin rotation
Forced two-factor solution

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.46	34.6	34.6
2	1.98	19.8	54.4

Structure matrix

Questionnaire item	Factor 1	Factor 2
Having to take medicines worries me	**0.79**	0.24
I sometimes worry about becoming too dependent on my medicines	**0.78**	0.22
I sometimes worry about the long-term effects of my medicines	**0.77**	0.21
My medicines disrupt my life	**0.62**	0.18
My medicines are a mystery to me	**0.60**	-0.10
My life would be impossible without medicines	0.17	**0.85**
My health at present depends on my medicines	0.17	**0.84**
Without medicines I would be very ill	0.35	**0.70**
My medicines protect me from becoming worse	-0.17	**0.59**
My health in the future will depend on medicines	0.35	**0.58**

General medical in-patients
(cleaned data n=90)

Principal components analysis
Oblimin rotation
Forced two-factor solution

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.60	35.9	35.9
2	2.30	22.9	58.9

Structure matrix

Questionnaire item	Factor 1	Factor 2
My health at present depends on my medicines	**0.88**	0.10
Without medicines I would be very ill	**0.84**	0.28
My life would be impossible without medicines	**0.81**	0.32
My medicines protect me from becoming worse	**0.80**	0.06
My health in the future will depend on medicines	**0.79**	-0.06
I sometimes worry about becoming too dependent on my medicines	0.00	**0.78**
I sometimes worry about the long-term effects of my medicines	0.12	**0.78**
My medicines disrupt my life	0.16	**0.70**
Having to take medicines worries me	0.10	**0.70**
My medicines are a mystery to me	0.09	**0.40**

Appendix9

Principal Components Analysis (PCA) of items assessing beliefs about medicines in general

BMQ GENERAL exploratory factor analysis

Diagnostic groupings	n	%
Chronic asthma	77	36
Diabetes	97	44
Haemodialysis	42	20
TOTAL SAMPLE	216	100

DEMOGRAPHIC DETAILS		
GENDER	**n**	**%**
Male	86	40
Female	130	60
AGE		
Mean	46.7	
SD	18.3	
Range	17.0 - 87.0	

BMQ General: Core items

Questionnaire statement
Without medicines doctors would be less able to cure people
Newer medicines are more effective than older ones
Most medicines are addictive
People who take medicines should stop their treatment for a while every now and again
Medicines only work if they are taken regularly
Medicines do more harm than good
Medicines are not natural remedies
All medicines are poisons
It is better to do without medicines
Natural remedies are safer than medicines
Stronger medicines are more dangerous than weaker medicines
Medicines are a necessary evil
Doctors place too much trust on medicines
If doctors had more time with patients they would prescribe fewer medicines
There is a big difference between a medicine and a drug
The medicine you get is more important than the doctor you see
Doctors use too many medicines
Most medicines are safe

BMQ General: Pool of items

Item	Mean	Std Dev
Without medicines doctors would be less able to cure people	3.13	1.54
Newer medicines are more effective than older ones	3.37	0.84
Most medicines are addictive	2.73	0.89
People who take medicines should stop their treatment for a while every now and again	2.54	0.91
Medicines only work if they are taken regularly	3.75	0.80
Medicines do more harm than good	2.24	0.85
Medicines are not natural remedies	3.13	0.92
All medicines are poisons	2.24	0.97
It is better to do without medicines	2.61	1.08
Natural remedies are safer than medicines	2.88	0.91
Stronger medicines are more dangerous than weaker medicines	3.24	0.90
Medicines are a necessary evil	3.06	1.10
Doctors place too much trust in medicines	2.90	0.93
If doctors had more time with patients they would prescribe fewer medicines	3.17	0.98
There is a big difference between a medicine and a drug	3.24	0.88
The medicine you get is more important than the doctor you see	2.87	1.14
Doctors use too many medicines	2.84	0.91
Most medicines are safe	2.72	0.92

Kaiser-Meyer-Olkin Measure of Sampling Adequacy = **0.78**

Bartlett's Test of Sphericity = **710.56**, $p < 0.001$

Exploratory factor analysis: Stage 2

Method

Principal components analysis
Non-orthogonal rotation (Oblimin)
Eigenvalues < 1 rejected.

18 items entered, 6 items rejected due to Kaiser Meyer Olkin (KMO) statistic < 0.7

Questionnaire item	KMO statistic
Without medicines doctors would be less able to cure people	0.45
Newer medicines are more effective than older ones	0.55
Medicines only work if they are taken regularly	0.57
There is a big difference between a medicine and a drug	0.45
The medicine you get is more important than the doctor you see	0.57
Most medicines are safe	0.42

Exploratory factor analysis: Stage 3

Method
Principal components analysis
Non-orthogonal rotation (Oblimin)
Eigenvalues < 1 rejected.

Medicines are not natural remedies	0.44	0.48	0.50

Exploratory factor analysis: Stage 4

Method

- Principal components analysis
- Non-orthogonal rotation (Oblimin)
- Forced two-factor solution.

Structure matrix

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.73	31.1	31.1
2	1.58	13.1	44.2
3	1.01	8.4	52.6

Structure matrix

Item	Factor 1	Factor 2	Factor 3
If doctors had more time with patients they would prescribe fewer medicines	0.75	0.12	0.28
Doctors place too much trust on medicines	0.75	0.27	0.16
Doctors use too many medicines	0.72	0.16	0.15
Natural remedies are safer than medicines	0.61	0.28	0.52
It is better to do without medicines	0.57	0.43	-0.04
Medicines are a necessary evil	0.52	0.12	-0.05
Medicines do more harm than good	0.32	0.74	0.11
People who take medicines should stop their treatment for a while every now and again	0.20	0.73	0.02
All medicines are poisons	0.22	0.66	0.26
Most medicines are addictive	-0.07	0.63	0.35
Stronger medicines are more dangerous than weaker medicines	0.16	0.22	0.86

Forced 2 factor solution based on Scree plot analysis

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.73	31.1	31.1
2	1.58	13.1	44.2

Item	Factor 1	Factor 2
If doctors had more time with patients they would prescribe fewer medicines	0.78	0.16
Doctors place too much trust on medicines	0.74	0.27
Doctors use too many medicines	0.72	0.16
Natural remedies are safer than medicines	0.69	0.37
It is better to do without medicines	0.53	0.38
Medicines are a necessary evil	0.48	0.08
Medicines do more harm than good	0.32	0.71
People who take medicines should stop their treatment for a while every now and again	0.19	0.68
All medicines are poisons	0.26	0.67
Most medicines are addictive	0.00	0.67
Medicines are not natural remedies	0.52	0.55
Stronger medicines are more dangerous than weaker medicines	0.33	0.41

Exploratory factor analysis: Stage 5

Method
Principal components analysis
Non-orthogonal rotation (Oblimin)
Eigenvalues < 1 rejected.

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	2.85	28.4	28.4
2	2.27	22.7	51.1

Structure matrix

Item code	Factor 1	Factor 2
If doctors had more time with patients they would prescribe fewer medicines	0.81	0.13
Doctors use too many medicines	0.79	0.15
Doctors place too much trust on medicines	0.75	0.26
Natural remedies are safer than medicines	0.70	0.32
Medicines do more harm than good	0.32	0.72
People who take medicines should stop their treatment for a while every now and again	0.20	0.71
All medicines are poisons	0.27	0.69
Most medicines are addictive	0.02	0.69

Kaiser-Meyer-Olkin Measure of Sampling Adequacy = **0.79**

Bartlett's Test of Sphericity = **342.65**, p< **0.0001**

BMQ GENERAL REPLICATION OF FACTOR STRUCTURE

1. Psychiatric patients

(cleaned data n=86)

Method

Principal components analysis
Non-orthogonal rotation (Oblimin)
Forced two-factor solution

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	3.18	39.7	39.7
2	1.40	17.5	57.2

Structure matrix

Item	Harm	Overuse
Medicines do more harm than good	**0.75**	0.27
Most medicines are addictive	**0.75**	0.04
All medicines are poisons	**0.74**	0.25
People who take medicines should stop their treatment for a while every now and again	**0.62**	0.43
Doctors place too much trust on medicines	0.11	**0.83**
If doctors had more time with patients they would prescribe fewer medicines	0.21	**0.82**
Doctors use too many medicines	0.46	**0.70**
Natural remedies are safer than medicines	0.54	**0.58**

BMQ GENERAL: REPLICATION OF FACTOR STRUCTURE

2. Cardiac patients
(cleaned data n=112)

Method
Principal components analysis
Non-orthogonal rotation (Oblimin)
Forced two-factor solution

Factor	Eigenvalue	% variance explained	Cumulative % variance explained
1	2.66	33.2	39.7
2	1.30	16.2	49.5

Structure matrix

Item	Harm	Overuse
Medicines do more harm than good	**0.63**	0.42
Most medicines are addictive	**0.76**	-0.01
All medicines are poisons	**0.53**	0.24
People who take medicines should stop their treatment for a while every now and again	**0.61**	0.23
Doctors place too much trust on medicines	0.22	**0.83**
If doctors had more time with patients they would prescribe fewer medicines	0.10	**0.79**
Doctors use too many medicines	0.33	**0.68**
Natural remedies are safer than medicines	0.26	**0.63**

BMQ-General factor scores

Range of scale = 4-20, **high** scores indicate **strong** beliefs

Illness grouping	n	General-Overuse	General-Harm
Combined	214	11.8	9.8
Asthma	76	11.7	10.3
Cardiac	112	12.8	10.0
Dialysis	42	12.8	9.7
Diabetes	96	11.5	9.3
Psychiatric	84	12.4	10.1

Appendix10

Principal Components Analysis (PCA) of combined BMQ-Specific and BMQ-General items

Table A10 Structure matrix obtained by PCA on combined items from the Specific and General medication belief factors on pooled data from the six illness groups comprising the main sample (total n = 524)

	ITEM S refers to medicines prescribed for a specific illness G refers to medicines in general	Factor 1 Specific Concerns	Factor 2 Specific Necessity	Factor 3: General Harm	Factor 4 General-Overuse
S	Having to take this medicine worries me	**.80**	.07	.15	.19
S	I sometimes worry about becoming too dependent on my medicines	**.78**	-.02	.14	.20
S	I sometimes worry about the long term effects of my medicines	**.76**	.07	.17	.15
S	My medicines disrupt my life	**.60**	.16	-.06	.33
S	My life would be impossible without medicines	.12	**.81**	-.07	.01
S	My health, at present, depends on medicines	.10	**.76**	-.04	-.04
S	Without medicines I would be very ill	.17	**.74**	-.08	.11
S	My health, in the future, will depend on medicines	.00	**.70**	-.09	-.01
S	My medicines protect me from becoming worse	-.11	**.65**	-.22	-.04
G	If doctors had more time they would prescribe fewer medicines	.16	-.10	**.81**	.09
G	Doctors place too much trust in medicines	.04	-.10	**.75**	.23
G	Doctors use too many medicines	.26	-.13	**.71**	.17
G	Natural remedies are safer than medicines	.01	-.12	**.47**	.45
G	Most medicines are addictive	.07	.06	.05	**.71**
G	Medicines do more harm than good	.22	-.11	.22	**.67**
G	All medicines are poisons	.16	.14	.21	**.58**
S	***My medicines are a mystery to me***	.39	.00	-.09	**.55**
G	People who take medicines should stop their treatment for a while every now and again	.33	-.12	.20	**.51**
	Eigenvalue	3.38	2.92	1.60	1.44
	Percentage variance explained	18.8	16.2	8.9	8.0
	Cumulative percentage variance explained	18.8	35.0	43.9	51.9

Appendix I I

Beliefs about Steroids Scales (BSS)

Steroid-Necessity

- My health at present depends on steroids
- My steroids are the most important part of my treatment
- Without my steroids I would be very ill
- Whether I feel better or worse depends on my steroids
- My steroids control my asthma symptoms

Cronbach alpha=0.83 n=75

Steroid-Concerns

- I sometimes worry about the long term effects of my steroids
- Having to take steroids worries me
- I sometimes worry about becoming too dependent on my steroids
- My steroids do more harm than good
- I have been given enough information about my steroids (REVERSE SCORING)

Cronbach alpha =0.78 n=75

SCORING:

Each of the 10 items was scored on a 5-point Likert scale where 1= strongly disagree, 2 = disagree, 3 = uncertain, 4= agree and 5 = strongly agree, reversed where indicated. Thus higher scores on each scale represent stronger beliefs in the concept represented by the scale

Results of Principal Component Analysis from which the scales were derived (see Section 8.3.1)

Principal Components Analysis with non-orthogonal (OBLIMIN) rotation

	Factor 1 Steroid-Necessity	Factor 2 Steroid-Concerns
My health at present depends on steroids	**0.82**	0.23
My steroids are the most important part of my treatment	**0.77**	0.04
Without my steroids I would be very ill	**0.77**	0.29
Whether I feel better or worse depends on my steroids	**0.73**	-0.03
My steroids control my asthma symptoms	**0.72**	0.16
I sometimes worry about the long term effects of my steroids	0.36	**0.78**
Having to take steroids worries me	0.46	**0.77**
I sometimes worry about becoming too dependent on my steroids	0.29	**0.76**
My steroids do more harm than good	-0.07	**0.73**
I have been given enough information about my steroids	-0.10	**0.60**
Percentage variance explained	**38.3**	**21.2**
Cronbach alpha	**0.83**	**0.78**